



**1 IN 120 ADULTS IN TORONTO ARE HIV POSITIVE.**

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Let's face the future together.

## **FACING THE FUTURE TOGETHER:**

An innovative response to the urgent HIV/AIDS crisis in Toronto

### **WHITE PAPER**

**World AIDS Day:** December 1, 2011

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**CASEY HOUSE**

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## Our Mission

Casey House provides exemplary treatment, support and palliative care for people affected by HIV/AIDS, in collaboration with our communities.

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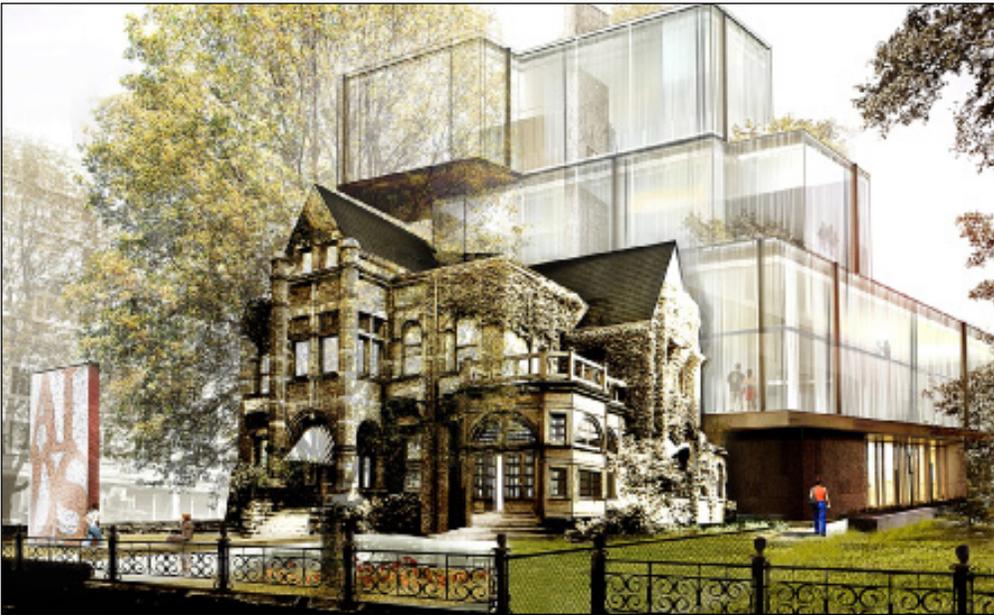
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CASEY HOUSE



**“It has been said that a great city is made up of great institutions. This new and prominent presence on Jarvis Street will firmly establish Casey House in the consciousness of the city, and will ensure it stands among the cultural, political, news, sporting, academic—and, indeed, other health care institutions—that together catapult this city to greatness.”**

Jaime Watt, Chair, Casey House Capital Redevelopment Campaign

## INTRODUCTION

# A letter from the Chair, Casey House Redevelopment Campaign

Founded in 1988, Casey House was the first freestanding HIV/AIDS facility in Canada. Casey House was leader in the creation of the compassionate palliative care movement that began in the late 1980s.

Over the years, Casey House has been lovingly maintained as a warm and welcoming environment for people living with HIV/AIDS, as well as their families and friends. For years, it provided a place to die with dignity—a place where gay men came to be cared for in their final stages of their battle with AIDS. Today, more and more patients come to Casey House to get better—and to get back on their feet. For many, Casey House stands as a beacon of hope.

There has been a dramatic evolution in the face of HIV/AIDS. As people live longer with the disease, our aging clients are confronted by complex and concurrent health issues. And, though many believe that the AIDS pandemic is behind us, infection rates continue at nearly the same levels as during the mid-1990s. The fact is, our 13-bed hospice and outreach model faces significant challenges in providing optimal health care for those living with HIV/AIDS today.

Thanks to the generosity of a visionary donor, we have the land to expand our home, and to do so at the current location, extending out to Jarvis Street. Casey House will again be an innovator in the provision of health care for people living with profound chronic disease. The vision and values of our founders, led by the indefatigable June Callwood, are a paramount consideration

for our planners and architects: while our new facility will house state-of-the-art health care facilities that embrace a “Net-Zero” philosophy to be as green and self-sustaining as possible, it will be a home first, providing compassionate care for each person who walks through its doors.

It is no secret that in the early 1980s, AIDS was associated with a high level of stigma and discrimination. As we break ground on this beautiful new building that will provide comprehensive, quality care for those living with HIV/AIDS, we do so with the knowledge that HIV no longer lives in the shadows. Casey House has engaged the renowned architectural firm Hariri Pontarini Architects to marry the heritage building at 571 Jarvis with our need for a modern health care facility. The Jarvis house restoration will be the architecturally stunning public face of our new facility, and will significantly contribute to the city’s efforts to return Jarvis Street to its former stature as a grand boulevard.

It has been said that a great city is made up of great institutions. This new and prominent presence on Jarvis Street will firmly establish Casey House in the consciousness of the city, and will ensure it stands among the cultural, political, news, sporting, academic—and, indeed, other health care institutions—that together catapult this city to greatness. We hope that you will be inspired to join us in making this dream a reality. Thank you for your support.

–Jaime Watt

## EXECUTIVE SUMMARY

# HIV/AIDS in Ontario today

Despite continued high rates of HIV infections, most Ontarians know little about the realities of HIV/AIDS treatment today. The HIV/AIDS crisis has widened in scope and complexity, presenting new and significant challenges for the health care system that demand an immediate and innovative response.

More people live with HIV today than ever before—not just around the world but right here in Toronto. Today, more than 1,000 people continue to be diagnosed with HIV each year in Ontario.<sup>1</sup> Alarming, in Toronto, more than a quarter of these individuals are under the age of 30.<sup>2</sup>

And those numbers are likely much higher: Dr. Robert Remis of the Ontario HIV Epidemiologic Monitoring Unit at the University of Toronto estimates that as many as one-third of Ontarians infected with HIV are as yet undiagnosed, unaware of their infection.<sup>3</sup>

Combine ongoing high infection rates with the longer life expectancy for people living with HIV/AIDS thanks to advances in treatment, and the result has been that the population of people living with HIV in Ontario grew 31 percent from 2003 to 2008 alone, and is continuing to grow.<sup>3</sup>

HIV/AIDS remains a pressing and growing urban health issue for the City of Toronto.

A recent Ipsos Reid survey of more than 900 Ontarians confirmed that 75 percent of respondents knew “nothing at all” or “just a little” about HIV/AIDS treatment and care. However, Ontarians are concerned and compassionate. Despite the ongoing stigma reported by people living with HIV/AIDS today, nine out of 10 survey respondents agree that society has a “moral obligation” to provide compassionate treatment to people living with HIV.<sup>4</sup>

## The changing face of HIV/AIDS

The face of HIV has changed dramatically in the past decade in Ontario. While the disease continues to deeply impact the gay community, infection rates have been increasing amongst women, youth, Aboriginals, people from countries where HIV is endemic, and people who are homeless, hard-to-house and under-housed. People living with HIV now are more culturally diverse, of varied ethnic origin and include increasing numbers of people living with mental health issues and addictions.

Many people with HIV live in socially and economically marginalized circumstances. Given the unpredictability of the illness, people living with HIV/AIDS are far more likely to be unemployed as compared to the general population. Results from a 1998 survey show only 38 percent of people living with HIV/AIDS were employed.<sup>5</sup>

Life with HIV/AIDS carries extra challenges, as the disease continues to be fraught with stigma and discrimination. Compounded by poverty and

**1 in 120 adults in Toronto today is HIV positive.**

**HIV/AIDS continues to be fraught with stigma and discrimination.**

physical frailty, people living with HIV/AIDS frequently face seemingly insurmountable challenges in accessing treatment and support. Their isolation further multiplies their risk for related mental health issues and addictions, homelessness or housing insecurity, abuse, unemployment, and worsening poverty.

The AIDS Bureau of Ontario reports that more than 50 percent of clients of Ontario HIV/AIDS organizations struggle with stigma, poverty, unemployment or food insecurity while 30 to 40 percent are coping with mental health issues, housing instability, problems accessing care, addictions, violence and a lack of life skills.<sup>6</sup>

Thanks to treatment advances, people with HIV are living longer, often well into their senior years. Current estimates indicate that by 2015, one-half of the population of Canadians living with HIV/AIDS will be 50 years or older.<sup>7</sup> However, the experience of growing old with HIV/AIDS can be extremely challenging. HIV doubles—and may even triple—cancer risk, even in the new treatment era.<sup>8</sup>

Even for those patients whose HIV-infection is “controlled” by medications, the ultimate effect on the human body of years or even decades of living with the virus and its associated medications is still unknown. The prognosis is further complicated by the damaging impacts of advanced age, disability and poverty.

### **HIV/AIDS: Increasingly complex health care needs**

Today, life with HIV means living with a chronic and cyclical illness, with unpredictable periods of wellness and illness. At Toronto’s Casey House, clients typically struggle with five or more major medical problems complicating their HIV disease, including liver and heart disease, osteoporosis, brain infections and cancer. Roughly half experience HIV-related neurocognitive impairment, making it hard to hold down a job, to live independently, or to adhere to medication regimes.

A 2008 report identified the need for increased capacity in Toronto for a wide range of health care services for people living with HIV/AIDS.<sup>9</sup> While continuing its existing programs, Casey House is poised to respond to this changing need, with a planned launch of a new Day Health Program in a purpose-built and state-of-the-art facility, to be opened in 2015-16.

The Casey House Day Health Program will provide some of Toronto’s most profoundly affected people living with HIV/AIDS with scheduled and unscheduled access to nurses, social workers, mental health and addictions workers, consulting psychiatrists and services provided by community partner agencies. Other health care services will include physiotherapy, a pharmacist and massage therapist, art therapy, as well as a hot, nutritious lunch. A key goal is early detection and screening for a range of health problems (e.g. opportunistic infections, cognitive changes, depression).

Every aspect of the Day Health Program will be fully consistent with our founders’ commitment to compassion and excellence in care for people living with HIV/AIDS.

**An individual who is aging with HIV becomes more susceptible to specific chronic conditions associated with older age such as cardiovascular disease, diabetes, arthritis, dementia and some cancers.**

This Day Health Program allows for the provision of cost-effective clinical care in the community. The program has shown an active consideration of the social determinants of health including nutrition and housing. As a result, this provides another option for an alternative level of care, once acute care is no longer necessary. In addition, this program may help to reduce the burden faced by overuse of emergency services.

Jim O’Neil, Executive Director,  
Community and Health Services  
Partnership and Program Director,  
Inner City Health Program,  
St. Michael’s Hospital

## Reducing the burden on the health care system

Ontario's health care system is increasingly affected by the expanding chronic care needs of an aging population. People living with HIV/AIDS have become part of this reality as they face high and recurring rates of hospitalization for acute episodes of illness, and require frequent access to specialists for consultation, diagnosis and treatment.

In addition to improving health care outcomes for people living with HIV/AIDS, Casey House's Day Health Program will contribute to the advancement of the Ontario health care system by demonstrating an effective model for health care delivery for people living with HIV/AIDS and other chronic diseases. An extensive interdisciplinary team approach will focus on the early detection, screening and intervention of emerging health issues, thereby reducing the need for other health services. A recent analysis estimates that the new Casey House Day Health Program would minimize the use of costly and high-demand health resources by its clients by more than halving the number of ER visits, EMS transports and hospital admissions they require.<sup>10</sup> This will free up costly and high-demand health care resources.

The redevelopment of Casey House, incorporating the new Day Health Program with its existing programs, will establish a centre of excellence for HIV/AIDS clinical care, education and research. It will successfully eliminate gaps in care and better target the use of health services by Casey House clients to reduce the overall burden of care. More people living with HIV/AIDS will be able to remain safe in their homes and out of hospital or long-term care.

The demands of the still-growing and unstable HIV/AIDS epidemic on the Ontario health care system are profound, and are projected to continue well into the future. Nine out of 10 Ontarians agree that the province needs new options for HIV/AIDS health care services that will reduce in-patient stays. As it did when it opened its doors in 1988, Casey House will once again lead the way.

**Casey House brings the experience, the drive and the passion to continue its founders' vision of excellent and compassionate health care for people living with HIV/AIDS.**

The Day Health Program is an exciting opportunity within a growing and important trend towards improving the integration of more medically-focused services with other practical services traditionally offered through community partner agencies.

The potential for a person living with HIV/AIDS to seamlessly transition between outreach, residential, day health and home care services—as well as improved access to community partner programming—will allow for service to be matched to their changing health care needs.

Murray Jose, Executive Director,  
Toronto People with AIDS Foundation

### **A SNAPSHOT OF HIV/AIDS IN TORONTO TODAY:**

- Every day, two Torontonians are newly infected with HIV
- More than 1 in 4 new HIV diagnoses in Toronto are among young people under 30
- 65% of new infections in Toronto occur in men who have sex with men
- Women represent 1 in 5 new HIV diagnoses in Toronto

## **THE PROBLEM:**

The rate of HIV infections in Ontario continues at nearly the same levels as during the mid-1990s, with approximately 1,000 Ontarians newly diagnosed each year.

Alarming, more than a quarter of these individuals are under the age of 30, facing decades of illness and significant adversity.

A widespread misconception exists that with medication, HIV/AIDS is a manageable disease.

In fact, for many—particularly as they age—HIV/AIDS is an unpredictable, marginalizing and frequently life-threatening illness for which there is no cure.

# An urgent and growing need for complex and multi-faceted HIV/AIDS care

The HIV/AIDS crisis in Ontario today has widened in scope and complexity, presenting new and significant challenges for the well-being of affected individuals—as well as for the health care system overall—that demand an immediate and innovative response.

The rate of HIV infections in Ontario continues at nearly the same levels as during the mid-1990s, with approximately 1,000 Ontarians newly diagnosed each year.<sup>1</sup> Alarming, in Toronto, more than a quarter of these individuals are under the age of 30,<sup>2</sup> facing decades of illness and significant adversity. A widespread misconception exists that with medication, HIV/AIDS is a manageable disease. In fact, for many—particularly as they age—HIV/AIDS is an unpredictable, marginalizing and frequently life-threatening illness for which there is no cure.

At Toronto's Casey House, where the mandate is to treat individuals experiencing advanced illness as a result of HIV infection, clients typically struggle with five or more major medical problems complicating their HIV disease. These frequently include liver and heart disease, osteoporosis, brain infections, and a variety of cancers that may or may not be directly related to long-term HIV/AIDS disease and its medications. Roughly half experience HIV-associated neurocognitive impairment, making it hard to hold down a job, to live independently, or to adhere to medication regimes.<sup>11</sup> Roughly half are age 50 or older, reflecting the aging demographic of people over the age of 50 living with HIV which is expected to reach 50 percent U.S.-wide by 2015,<sup>7</sup> with Canadian rates expected to be similar.<sup>12</sup>

The face of HIV/AIDS is changing in Ontario. The population of people living with HIV/AIDS is becoming increasingly complex in its treatment needs, and harder to reach due to marginalization and other circumstances. Although gay men continue to be most affected by the disease, infection rates are growing in other populations. Many people infected with HIV live in marginalized circumstances due to mental illness, addictions or poverty and so experience greater barriers to treatment. And overall, the "Greying of AIDS" is a phenomenon that will have widespread impact on the provision of HIV/AIDS care as older individuals develop more chronic diseases layered on top of their HIV-associated illnesses.

Uncertainty is a well recognized source of emotional distress, fear, anxiety, and depression for people living with HIV. With medical advances, individuals living with HIV often faced new uncertainties as they struggled to come to terms with planning for life rather than imminent death. Many had to renegotiate their life priorities and reconstruct their identities as a person living with a long-term illness. Hence, the uncertainty of living with a chronic illness may be considered as challenging as the knowledge of impending death.

O'Brien, Kelly et al. Exploring Disability from the Perspective of Adults Living with HIV/AIDS: Development of a Conceptual Framework. *Health and Quality of Life Outcomes* 2008; 6:76.

## Ontarians know little about HIV/AIDS treatment today, but feel deep concern and compassion

Despite continued high rates of HIV infection, most Ontarians know little about the realities of HIV/AIDS treatment today. A recent Ipsos Reid survey of over 900 Ontarians confirmed that 75 percent of respondents reported that they know “nothing at all” or “just a little” about HIV/AIDS treatment and care.<sup>4</sup> This finding is further substantiated by results from recent focus groups of Torontonians in sessions conducted by Casey House: participants said they are unfamiliar with HIV/AIDS and are uncertain about how the ongoing growth of HIV/AIDS will affect future generations.<sup>13</sup>

However, Ontarians are concerned and compassionate. Despite the ongoing stigma reported by people living with HIV/AIDS today, Ontarians overwhelmingly champion the well-being of people living with HIV/AIDS: Nine out of 10 survey respondents agree that society has a “moral obligation” to provide compassionate treatment to people living with HIV, no matter how they contracted the disease.

Not surprisingly, the cost of providing health care for a growing population of people living with HIV was a concern for Ontarians, with seven out of 10 respondents saying they are concerned about the issue.

Consistent with the overlap between Ontarians’ compassion toward people living with HIV/AIDS and their concern about rising health care costs, an overwhelming majority—nine out of 10 Ontarians—agreed that the province needs new options for HIV/AIDS health care services that will reduce patient hospital stays.

### HIGHLIGHTS FROM THE IPSOS REID SURVEY: ONTARIANS SUPPORTIVE OF INNOVATION AND COMPASSION IN HIV/AIDS CARE

75% of respondents say they know little about the realities of HIV/AIDS treatment

75% of Ontarians disagree with the statement that adults with HIV/AIDS deserve little sympathy due to risky behaviour

9 out of 10 Ontarians agree that society has “a moral obligation” to provide compassionate treatment for people living with HIV/AIDS, no matter how they contracted the disease

9 out of 10 Ontarians agree that Ontario needs new options for HIV/AIDS health care services that will reduce patient hospital stays.

## An ongoing urban health crisis

More people live with HIV today than ever before—not just around the world but right here in Toronto. When Casey House first opened in 1988, the founders imagined that a cure for HIV/AIDS would be found by now, and the disease managed. Instead, more than 1,000 people continue to be diagnosed with HIV each year in Ontario.<sup>1</sup> Current estimates indicate that 18,000 people are living with HIV/AIDS in Toronto.<sup>1</sup> Compare that with an adult population in the City of Toronto census region of 1,947,445,<sup>15</sup> and we find that 1 in 120 adults in Toronto today is HIV positive.

HIV/AIDS was first identified in 1981. Now, 30 years later, HIV/AIDS remains an urban health crisis in Toronto, bringing profound and wide-ranging challenges into the lives of the people infected, as well as for their loved ones and care providers.

Ongoing epidemiologic research conducted at the University of Toronto confirms that HIV/AIDS remains a pressing and growing urban health issue for the City of Toronto. Combine ongoing high infection rates with the longer life expectancy for people living with HIV/AIDS thanks to advances in treatment, and the result was 31 percent growth in the HIV-positive population from 2003 to 2008 alone, with numbers continuing to rise.<sup>3</sup>

Toronto, and particularly its downtown core, is the epicentre for HIV/AIDS in Ontario and even Canada. Toronto is home to more than one-quarter of the 65,000 individuals currently living with HIV across Canada.<sup>14</sup> Prevalence of HIV/AIDS is particularly high in the neighbourhoods closest to Casey House.<sup>23</sup>

**1 in 120**  
adults in Toronto is now  
HIV-positive.

Young people under the age of 30 represent more than one-quarter of new infections in Toronto.

## HIV/AIDS IN TORONTO

# The changing face of HIV/AIDS

The face of HIV has changed dramatically in the past decade in Ontario. While the disease continues to deeply affect the gay community, infection rates have been increasing among women, youth, Aboriginals, people from countries where HIV is endemic, and people who are homeless, hard-to-house and under-housed. People living with HIV now are more culturally diverse, of varied ethnic origin and include increasing numbers of people living with mental health issues and addictions.

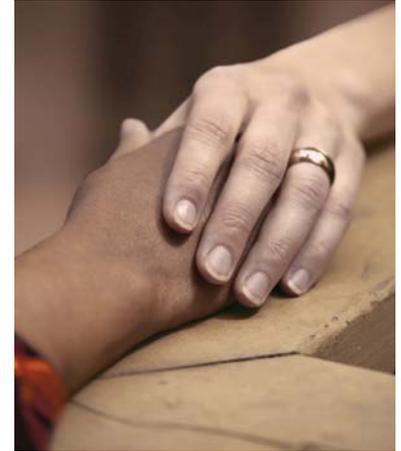
Overall, providing care for these individuals can pose a tremendous challenge to families, friends and health care providers, as the care needs of this population are multi-faceted and complex in scope. These individuals can be hard to reach, as the deep stigma and societal isolation they experience due to their disease and associated needs frequently create barriers to health care access. Even getting to a much-needed medical appointment can be an impossible challenge for an impoverished HIV-positive mother who lacks child care or transit money and who is terrified of the very real consequences of stigma in her community if people find out she is HIV-positive.

## Young adults under 30

In 2009, young people under the age of 30 represented more than one-quarter of new infections in Toronto.<sup>2</sup>

The implications of high infection rates amongst young people are profound: many decades of viral infection and associated medications mean possible long-term effects on an individual's heart, liver, kidneys and bones, along with higher risk for other adverse reactions to treatment. In addition to the long-term health effects of a disease as challenging as HIV, the longer one lives with an episodic disability, the more likely he or she is to experience other damaging impacts on well-being such as poverty, insecure housing or nutrition, and the erosion of social networks.

Over time, these individuals will require significantly more complex health care and social supports than their non-HIV infected counterparts, creating additional strain on Ontario's health care and social support programs.



## JOY: A MOTHER'S LIFE WITH HIV/AIDS

Like many single mothers who are poor, Joy struggles with isolation. HIV isolates her even more. "There is terrible stigma in my community," explains Joy, who is originally from East Africa. "People who I thought were friends, when they found out I had HIV, they wouldn't come near me. What do they have to be afraid of?"

Four years ago, Joy was told that she had only months to live. Today, though she continues to be very fragile and lives with constant pain, the care she receives from Casey House and other community partners gives her hope for her future, and for that of her son. "HIV wasn't my plan, but life doesn't always turn out the way you want it to be," says Joy. "It's not easy to be a single mother with HIV. Without help, I don't think I could survive. I know I couldn't. But today, I have hope. I'm raising my son to be strong and independent, and to give back to society."

## Women and HIV

HIV infection rates among women have remained high for some years now. This is driven by the immigration rates of women from countries where HIV is endemic (representing more than half of new infections among women).

Women now account for one-quarter of all new adult positive HIV tests in Ontario.<sup>156</sup>

## Aboriginal people and HIV

Aboriginal people comprise less than 4 percent of Canada's population but make up over 12 percent of all new HIV infections.<sup>14</sup> Aboriginal women are hardest hit, representing roughly half of all positive tests among Aboriginal people as compared with a ratio of one in five for women of other ethnicities.<sup>14</sup> The average age at diagnosis for an Aboriginal person tends to be younger, with high rates for youth aged 15-29 years.<sup>14</sup>

## HIV, stigma and poverty: A vicious cycle

Many people with HIV live in socially and economically marginalized circumstances. Given the unpredictability of the illness, people living with HIV/AIDS are far more likely to be unemployed than people in the general population. Results from a 1998 survey show only 38 percent of people living with HIV/AIDS were employed.<sup>5</sup> A diagnosis of HIV/AIDS is often the beginning of a downward spiral that can eventually lead to poverty.

Life with any chronic illness is exhausting, frequently unpredictable and commonly isolating. But life with HIV/AIDS carries extra challenges, as the disease continues to be fraught with stigma and discrimination. Compounded by poverty and physical frailty, people living with HIV/AIDS frequently face seemingly insurmountable challenges in accessing treatment and support. Their isolation further multiplies their risk for related mental health issues and addictions, homelessness or housing insecurity, abuse, unemployment, and worsening poverty.

The AIDS Bureau of Ontario reports that clients of Ontario HIV/AIDS organizations face significant health and social barriers to well-being, with more than 50 percent of clients struggling with stigma, poverty, unemployment or food insecurity while 30 to 40 percent are coping with mental health issues, housing instability, problems accessing care, addictions, violence and a lack of life skills.<sup>6</sup>



### TONIE: NOT QUITTING LIFE

In her early 40s, Tonie has been HIV-positive for nearly 20 years. She has come to rely on Casey House not only for helping her to manage her health care, but also for a network of friendships and support that she can't get elsewhere.

"So what if I'm HIV? People find out and they treat you differently. It makes me angry. I'm not dead. I'm not helpless, not yet. I just have a disease. Since I got this virus, I've become a better person. I'm not quitting on myself. And the people around me know I'm not quitting, either."

## **Toronto's HIV population is greying**

Thanks to treatment advances, people with HIV are living longer, often well into their senior years. This is a reality that was unthinkable as little as 15 years ago, when a diagnosis of HIV/AIDS meant certain death. Current estimates indicate that by 2015, one-half of the population of Canadians living with HIV/AIDS will be 50 years or older.<sup>12</sup>

However, the experience of growing old with HIV/AIDS can be extremely challenging. HIV doubles—and may even triple—cancer risk, even in the new treatment era.<sup>8</sup> Even for those patients whose HIV-infection is “controlled” by medications, the ultimate effect of years or even decades of these new and powerful medications on the human body is still unknown. The prognosis is further complicated by the damage caused by long-term viral suppression, advanced age, disability and poverty. An individual who is aging with HIV becomes more susceptible to specific chronic conditions associated with older age such as cardiovascular disease, diabetes, arthritis, dementia and some cancers. These diseases may be associated with higher incidence and poorer outcome due to HIV infection, or may simply occur with greater frequency due to older age.<sup>12</sup> Clinicians must also be on the lookout for possible interactions of medical treatments for these concurrent diseases with the treatment for HIV.

As many as 50 percent of people living with HIV/AIDS report cognitive difficulties, which can be associated with objective neuropsychological impairments and depression.<sup>17</sup> These brain impairments bring with them decreased ability to adhere to medication regimes and increased risk-taking behaviour, posing a significant threat to the prevention and management of HIV,<sup>18</sup> as well as to the independence and quality of life of affected individuals.



### **JAMES: COMING HOME**

“All the sadness in my life, all the losses I’ve had... My whole life fell apart 10 years ago when my best friends died of AIDS and I had nobody left. I was drowning under it all.

Casey House has been the solid rock I could cling to, in all the turbulence of my life. Whenever I come through the door at Casey House, it’s like coming home.”

## Increasingly complex health care needs of people living with HIV today

HIV/AIDS is a tremendously challenging health condition to treat. Physicians must be experts in the complex and rapidly evolving field of antiretroviral drug therapies. They must also be skilled in the diagnosis, prevention and treatment of associated and often multiple conditions including opportunistic infections, cancers, respiratory disease, kidney disease, lipid disorders and psychiatric disorders.

Over the course of their illness, individuals living with HIV are faced with high and recurring rates of hospitalization for acute episodes of illness, and require frequent access to specialists for consultation, diagnosis and treatment. At the same time, most need a broad range of services and supports including mental health, harm reduction/addictions, housing, transportation, food security and other support services.

People living with multiple and complex health conditions require more effective coordination of care to ensure all of the patient's conditions are addressed. This requires support from an interprofessional team of health providers that works across disciplines to coordinate and integrate care. Studies show that when primary care providers are more appropriately engaged in care, patients less frequently use unplanned walk-in and emergency room services and are more likely to maintain an overall improved state of health.<sup>19</sup>

As people living with HIV/AIDS who have access to antiretroviral therapy live longer, the long-term impacts of HIV and its treatments, in combination with aging itself, may include increased prevalence of concurrent conditions, such as arthritis, fractures from osteoporosis, diabetes, some forms of cancer, and depression or other mental illnesses. The common feature of these other conditions are that they can all be episodic both in nature and impact. As such, people living with HIV/AIDS may experience several episodic conditions concurrently, all with different fluctuations in their functioning and health. Thus, the corresponding need for rehabilitation is expanding in order to prevent or manage such disabling impacts and maintain or promote improved quality of life.

Canadian Working Group on HIV and Rehabilitation. E-Module for Evidence-Informed HIV Rehabilitation, 2011.

**Casey House clients typically struggle with five or more significant illnesses in addition to their HIV infection. These include liver and heart disease, osteoporosis, a variety of cancers and neurocognitive disorders.**

### **An episodic disability, with fluctuating severity over time**

Life with HIV today means living with a chronic and cyclical illness, with unpredictable periods of wellness and illness. The severity and duration of these periods of disability can vary widely depending on access to effective treatment. Life event triggers and other circumstances in a person's life can also impact their health, such as starting or changing medications, experiencing a concurrent illness or suffering a loss, or weakness in their network of social support or poor access to housing and proper nutrition.

The fact that HIV/AIDS has largely become an episodic disability means health care solutions must be available that are flexible, adaptive and responsive to an individual's fluctuating need.

### **The population served by Casey House: Older, sicker, harder to reach, with complex and layered health care needs**

At Casey House, where the mandate is to treat those most profoundly affected by HIV/AIDS, clients typically struggle with five or more significant illnesses in addition to their HIV infection. These frequently include liver and heart disease, osteoporosis, and a variety of cancers that may or may not be related to HIV/AIDS disease or medications. Approximately half experience some form of HIV-associated neurocognitive disorder, often resulting in memory loss, reduced ability to problem-solve, reduced adherence to treatment, increased risk-taking activities, decreased decision-making capacity, and onset of mental health symptoms (for example: anxiety, obsessive compulsive disorder and delusional thinking). A recent chart review of 87 patients admitted to Casey House's in-patient program in 2008 revealed that patients were taking an average of 12 medications each at the time of admission. Seventy-four percent had been prescribed antiretroviral drugs but had a self-reported adherence rate of only 55 percent."

Not surprisingly, depression and addictions are also common among Casey House clients, with three-quarters of the in-patient population experiencing mental health challenges and 41 percent reporting drug use. Health care professionals at Casey House report that this number continues to grow. The most common psychiatric disorders were cognitive disorders including dementia, depressive disorder and addictions.

Clients cared for at Casey House require a multi-faceted approach to care: 75% of Casey House in-patient clients experience significant mental health challenges.

Halman, Mark et al. Complex Care Needs of Patients with Late-Stage HIV Disease: A Retrospective Study. Preliminary Report. Casey House, 2011.



### **BRUCE: NOTHING TO HIDE**

"The Day Health Program for me will mean peace of mind, proper nutrition and a place to go and be social, while accessing the services I need to be healthy.

The nutritional program is really exciting for me, because you can't be healthy when you don't have access to proper food. But most of all, what I'm looking forward to is a place to go where people don't expect me to be anything but who I am. Where there's nothing to hide. Because you need that when you're working so hard to get back to health."

When treatment is delayed or interrupted, symptoms can progress so that when the individual enters treatment, his or her health care needs can be extremely complex. This results in negative consequences for the individual's health as well as increased costs and strain on our health care system.

## REMOVING BARRIERS TO CARE

# Barriers to HIV/AIDS treatment lead to worse outcomes for the individual, with increased strain on our health system over time

Many people with HIV/AIDS delay or interrupt treatment for a variety of reasons. Many experience systemic barriers to health care in general. Deep-seated HIV stigma can lead people to profoundly fear disclosure, so they avoid seeking care. Others avoid getting tested, frightened by the potential results. Still others do not access health care or interrupt their care regimens because of concurrent health issues, including addictions or mental illness, or because of a real or perceived side effects from the medications.

When treatment is delayed or interrupted, symptoms can progress so that when the individual enters treatment, his or her health care needs can be extremely complex. Unfortunately, this results in negative consequences for the individual's health as well as increased costs and strain on our health care system.

A recent study of the cost of medical care for HIV-infected patients in southern Alberta showed that costs rose by as much as 74 percent for those patients with advanced stage disease.<sup>20</sup> Patients with advanced illness required more medications as well as more frequent use of in-patient and out-patient services.

At the same time, hospitals today face increasing demand for beds and are continually challenged to reduce wait times for emergency care and to facilitate timely, appropriate discharge. New approaches to care that will be more comfortable and healthier for patients, as well as more cost-effective, are in continual demand.

A substantial number of people who are waiting for long-term care—and some who are currently in long-term care—could be cared for at home or in “assisted living” facilities if they were provided with the right kind of support.

Andreas Laupacis, Irfan Dhalla and Karen Born. Waiting for Long-Term Care in Ontario. Healthy Debate, March 16 2011. Online at [www.healthydebate.ca](http://www.healthydebate.ca)

Social isolation is a significant factor of vulnerability for HIV-positive older adults, as revealed in the ROAH study of HIV-positive older New Yorkers. Seventy percent of 914 respondents lived alone, as compared to 39% of all New Yorkers over 50. A lack of social networks and supports leaves older adults with less resources, making them more susceptible to issues such as depression, bereavement, poor mental health, and substance abuse, which are all commonly associated with aging and HIV.

Cahill, Sean et al. Growing Older With the Epidemic: HIV and Aging. *Gay Men's Health Crisis Report*, 2010

Most people living with HIV today face an uncertain 'roller coaster ride' during which the disabling effects of HIV, its treatment and opportunistic infections are unpredictable.

## GAPS IN CARE

# Gaps in health care services for people living with advanced HIV infection

A 2008 report conducted for Casey House<sup>9</sup> identified that the most predominant under-served health care needs of people living with HIV/AIDS who are at risk of deteriorating health are related to factors associated with the social determinants of health (i.e., housing, food/nutrition, connection/social inclusion and steady income).

The report also identified the need for increased service capacity in Toronto for:

- Personal and health stabilization
- Access to basic and specialized health care
- Mental health counselling and support, substance use counselling and psychotherapy services
- Harm reduction supplies
- Medication-related services
- Food and nutrition
- Foot care
- Dental care
- Care coordination and advocacy
- Physiotherapy
- Occupational therapy
- Rehabilitation services

Also noted in the report was the importance of a "population health approach": acknowledgment that there is a range of social, economic and physical environmental factors that contribute to health. This approach recognizes that not everyone has the access to health care services and supports that are required to maintain their health.

Twenty years of advances in antiretroviral medication have transformed HIV disease from a 'terminal' condition into a lifelong episodic illness for many people. Rather than facing the steady decline in health towards death that characterized the first decade and a half of the epidemic in Canada, most people living with HIV today face an uncertain 'roller coaster ride' during which the disabling effects of HIV, its treatment and opportunistic infections are unpredictable.

Canadian HIV/AIDS Legal Network.  
Income Security for People Living with HIV/AIDS in Canada. Information Sheet. December 2005.

Chronic disease currently accounts for an estimated 55 percent of direct and indirect health care costs for our province. HIV/AIDS has become one of these diseases.

## REDUCING PRESSURE

# Health care system requires innovative responses to complex chronic care needs

Chronic disease currently accounts for an estimated 55 percent of direct and indirect health care costs for our province.<sup>21</sup> HIV/AIDS has become one of these diseases.

As our population ages, the burden of chronic disease management on our health care system will increase, with resources becoming more scarce as a result. The health care system must find new ways to move away from hospital-based services toward a greater reliance on community providers.

Many organizations have developed home and community care programs to reduce pressure on the health care system, with some success. A recent analysis sponsored by the Ontario Community Provider Associations Committee and the Change Foundation estimated that home and community care contributes \$150 million in annual savings and value to the health care system.<sup>22</sup> Ontario's Community Care Access Centres (CCACs) and smaller community-based health and social service organizations such as local Community Health Centres and AIDS service organizations strive to reduce hospital admissions and relieve pressure on emergency departments.

Organizations like Casey House that demonstrate the capacity to be innovative and solution-focused will be in a stronger position to meet the expanding and multiple needs of Toronto's growing population of people living and aging with HIV/AIDS.

People with chronic conditions can benefit from access to professionals with special skills, including pharmacists to review their medications, dietitians to provide advice on nutrition and primary care providers to monitor key health indicators. The best case is when people have access to a team that meets all their health-related needs and engages them in self-management by helping them develop their own action plans and set personal goals.

Health Quality Ontario, *Quality Monitor*, 2011

## **THE SOLUTION:**

The next evolution of care for people living with HIV/AIDS is upon us.

With higher numbers of people living longer with HIV than ever before, there is compelling need for Casey House to expand its continuum of health care services through the addition of a Day Health Program.

Input and advice gathered from clients, their families and other AIDS service organizations has been fundamental in shaping the design of the new Casey House Day Health Program, which will offer coordinated access to a wide range of health care services and effective links to other important health care and community resources. The program will also introduce opportunities for meaningful research and health professional education.

## THE CASEY HOUSE SOLUTION

# Facility expansion to include a new and innovative Day Health Program

### Casey House: A history of leadership in innovative and compassionate response

Founding volunteers opened the door to Casey House in 1988 in response to the urgent need for appropriate and compassionate health care for HIV/AIDS patients at a time when infection meant certain death. Casey House began service to this community with 13 beds, pioneering a compassionate hospice-based end-of-life approach. Casey House was the first dedicated hospice in Ontario, and the first HIV/AIDS hospice in Canada. At the time, it was a leader not only in HIV/AIDS care, but in palliative care.

As HIV/AIDS treatment advanced, people began to live longer with the disease and wished to remain at home with support. Once again, Casey House led the way, launching in 1992 a home care program funded by concerned donors. Some years later, the Toronto Central CCAC also began to contribute some financial support.

Recognizing that individuals who are homeless are not able to access home-based care, Casey House soon partnered with Sherbourne Health Centre to launch a community nursing program, bringing expert HIV/AIDS care to the streets via the Sherbourne Health Bus.

Today, many more people living with HIV/AIDS are experiencing the disease as a complex chronic disease with episodic and fluctuating need for increased care. While continuing its existing programs, Casey House is poised to once again innovate in response to this changing need, with the planned launch of a new Day Health Program in a purpose-built and state-of-the-art facility, to be opened in 2015-16.

The Casey House Day Health Program will fill the gap between acute hospital care and episodic care provided in the home by our Home Care and Outreach teams. It will provide the critical, day to day, comprehensive care that is needed by people living with HIV/AIDS. It will enable Casey House to help our clients achieve the expanded concept of greater health which includes barrier-free access to health care professionals, but also connectedness to those who have a shared life experience, the opportunity to learn and teach one another, nutritious meals, recreational activities and a sense of community.

*I'll have done my job well if I create environments that give people the tools they need to live the best life possible, and if they live a longer life because of it.*

Karen de Prinse, Chief Nursing Executive and Director of Clinical Programs, Casey House

## **The Day Health Program: The evolution of HIV/AIDS care, informed by people living with HIV, their families, and partner organizations**

The next evolution of care for people living with HIV/AIDS is upon us. With higher numbers of people living longer with HIV than ever before, the time has come for Casey House to expand its continuum of health care services through the addition of a Day Health Program.

In planning the Day Health Program, Casey House held focus group discussions with people living with HIV as well as those identified from a recent community needs assessment, to identify their concerns and ensure that the new program will eliminate gaps in health care faced by the growing and diverse HIV-affected population in Toronto.

A community-based steering committee that includes clients, family members and partner organizations will actively oversee and conduct ongoing evaluation, ensuring that the program continues to appropriately evolve and adapt in response to changing needs. The input of people living with HIV/AIDS will be integrated into all aspects of planning, service delivery and accountability.

While the Casey House Day Health Program will be the first of its kind in Ontario, the planning process has been deeply informed by the positive outcomes established at the Dr. Peter AIDS Foundation in Vancouver, where a highly successful Day Health Program has been flourishing for a decade. The new Casey House—providing a continuum of care via its in-patient, home care and day health programs—will be the first complex chronic disease care facility of this kind in Ontario.

The Day Health Program will diminish barriers to care for people living with advanced HIV/AIDS who increasingly experience recurrent and long-term complex health issues coupled with emerging health conditions. The episodic nature of their illness requires a range of health care approaches that will be enhanced once the Day Health Program is added to existing Casey House services including in-patient sub-acute and respite care, home nursing support, clinical outreach and support.

We firmly support the development of the Day Health Program to improve the health of our clients. This program will benefit many people living with HIV/AIDS who are currently not receiving the health services that they require due to the stigma and discrimination they face daily.

PASAN is committed to a collaborative partnership with Casey House to expand services to address the unmet health care needs of people in Toronto who live with substance use challenges and are living with HIV/AIDS.

Anne Marie DiCenso, Executive Director, PASAN - Prisoners with HIV/AIDS Support Action Network

## Planned programs and services

The Casey House Day Health Program will provide some of our city's most profoundly affected people living with HIV/AIDS with highly responsive and effective health care including scheduled and unscheduled access to nurses, social workers, mental health and addictions workers, and consulting psychiatrists. Team members will liaise with the clients' treating physicians to ensure seamless, comprehensive health care. Other health care services will include physiotherapy, a pharmacist and massage therapist, art therapy, as well as a hot, nutritious lunch.

A significant number of clients currently accessing in-home supports will migrate to the Day Health Program as Casey House expands its ability to serve the growing population of people living with HIV/AIDS.

Further, the program will be open to families and loved ones so that they can access help and get a break from care, thanks to a daytime respite program.

Every aspect of the Day Health Program will be fully consistent with Casey House's ongoing commitment to both compassion and excellence in care for people living with HIV/AIDS, continuing to embrace our founders' vision.

## A more agile response

To ensure that the Casey House Day Health Program successfully engages the diverse population of people living with HIV/AIDS, collaborative partnerships and satellite sites are being developed to support participants' need for treatment and palliative support in their community environment of choice. Mobilizing services to various community locations will significantly improve access for women, people from countries where HIV is prevalent and those from visible minority groups for whom stigma makes them afraid to access care in an identified HIV care facility.

Day Health Program services will be focused on the health care needs of people living with HIV/AIDS and their families/supporters along the continuum from early onset of symptoms to end-of-life care. Health care services that focus on early detection and screening for a range of health problems (e.g. opportunistic infections, cognitive changes, depression) will be coupled with comprehensive nursing and allied health treatment, along with interventions and support to promote and maximize the health and well-being of people living with HIV/AIDS.

The Day Health Program model will offer flexibility for clients to access and receive services through multiple entry points and link with existing community-based services and other health providers.

In addition to improving health care outcomes for people living with HIV/AIDS, the Casey House Day Health Program will contribute to the advancement of the Ontario health care system by demonstrating an effective model for delivery of health care supports to people living with HIV/AIDS and other chronic diseases.

## THE CASEY HOUSE DAY HEALTH PROGRAM: PLANNED SERVICES

The new Day Health Program will provide clients and their loved ones with access to an inter-professional team that will support them from the onset of symptomatic HIV to end-of-life care.

Much-needed services will include:

Support and management of medication regimes

Wound and skin care management

Post-procedure and post-operative care

Health assessments

Health teaching and education

Treatment and intervention for mental health and substance use

Rehabilitation therapies (physical, occupational) and massage therapy

Hot and nutritious meals and nutritional counselling

Advocacy and referral to specialized health care resources and to community-based services

Recreational opportunities that address social isolation, improve well-being and build a social network

Harm reduction interventions related to high-risk activities

A full range of health, social and supportive care with respect to death and dying

## The Day Health Program will revolutionize the way HIV/AIDS health care services are delivered in our province.

### Help with navigating uncharted waters

The Casey House Day Health Program professional staff (eg. registered nurses and social workers) will support a greater number of clients by helping them to access appropriate care and support, improving their health and well-being so that they can find stable footing. This intensive case management approach will also decrease hospital admissions for this population and demonstrate a working health service delivery model that is transferable to other diseases.

### Revolutionizing HIV/AIDS care in Ontario

Casey House will continue to be a centre of excellence for HIV/AIDS care in Ontario, offering expertise in nursing, social work, pharmacy, nutrition, occupational therapy, physiotherapy, social recreational therapy, massage, music and art therapy, counselling and case management coupled with collaborative partnerships and relationships with psychiatry, family practice, and infectious diseases specialists. In-house expertise in mental health, substance use and harm reduction will ensure services are tailored to the individual needs of the diverse client base that continues to struggle with HIV/AIDS.

Casey House is working with the Toronto HIV/AIDS Network, providers and people living with HIV/AIDS to find innovative ways to reach out to underserved communities, with a focus particularly on hard-to-reach populations such as women from endemic countries and people living with mental health challenges and addictions.

### Addressing knowledge gaps

The needs of Ontarians living with HIV/AIDS are becoming increasingly diverse, and will continue to expand in complexity and scope well into the future. Rigorous, relevant, clinical and community-based research will be critical to addressing knowledge gaps about advanced HIV/AIDS treatment, ensuring that province-wide approaches to care are based on solid evidence.

Casey House's Research Planning Task Force was developed in partnership with community-based agencies, research funders, clinicians, and people living with HIV/AIDS. Its plan calls for Casey House to develop its unique role in research via participation in external projects and internal studies. The patient population served at Casey House is unique in its overall disease complexity, with the majority of clients experiencing the effects of long-term disease progression. An understanding of this particular patient population will be fundamental in forecasting future need as more Ontarians age with the disease.

I worked as a Community Nurse for the Casey House Community Outreach program for one year before joining the nursing staff at the residence in 2011. In many cases, I was the only person that my client would see for two weeks at a time; and, through those clients, I met many others who were HIV-positive and had no access to the resources or assistance whatsoever. All of my clients had my phone number, and many would call me every day with questions or concerns. Much of the time, the only advice I could give them would be to go to Emergency.

The Casey House Day Health Program will provide these socially isolated clients with the kind of care that they need. They will be able to see nurses, get their medication, have a meal and enjoy some social interaction at the same time.

This will make a big difference in the lives of those living with HIV/AIDS.

Julianne Lavoie, RN, Casey House

Casey House has promoted knowledge transfer in Toronto through its annual free symposia and seminars offered to clinicians, physicians and staff of AIDS service organizations. A growing number of student placements take place at Casey House, enabling future clinicians to experience first-hand the complexity of care required by the unique populations served at Casey House.

These and other research and knowledge exchange initiatives at Casey House will advance its research capacity in preparation for the significant and innovative research potential presented by the Day Health Program.

### Reducing the burden on our health care system

Given the extensive interdisciplinary team approach that will focus on the early detection, screening and intervention of emerging health issues for Casey House clients, it is less likely that emergency or urgent health care needs will develop. This more comprehensive approach to care will reduce the need for other health services. A recent analysis estimates the new Casey House Day Health Program would minimize the use of costly and high-demand health resources by its clients by more than halving the number of ER visits, EMS transports and hospital admissions they require. It would also reduce by two days the average length of stay for those who require hospital admission, decrease visits to primary care physicians, and dramatically cut the number of visits to psychiatrists.

This decreased use of emergency services, along with fewer visits to physicians and specialists, will free up costly and high-demand health care resources. Given that people often experience long wait times for emergency care and face lengthy waitlists for access to more specialized health services, it is clear that the new Casey House Day Health Program will positively impact Ontario’s health care system.

	Average # of Visits	
	Per Client Annually (Current)	Per Client Annually (After Introduction of Day Health Program: Estimate)
Emergency Visits	3.1	1.30
Hospital Admissions	4.0	1.38
Primary Care Physicians	6.7	6.33
Psychiatrist	6.9	1.88

Current use of health services by Casey House community clients, projecting the extent to which the Day Health Program will reduce their need for hospital and specialist services<sup>10</sup>

Each person living with HIV/AIDS has a unique and diverse set of needs which currently require visits to many professionals in many locations across the city. The Casey House Day Health Program will be a central hub, located in the community, where people living with HIV/AIDS can share their personal story and access support for more of their health care needs in one place. It will be a place where we will listen to members of our community and respond to their needs with a holistic approach that embraces all of the intersecting physical, emotional and social needs.

Bill O’Leary, Social Worker,  
Casey House



## The right solution for the right reasons

This responsive approach to meeting the fluctuating needs of our client population will ensure that people are able to remain safe in their homes for as long as possible, with effective, targeted and compassionate health care support.

The redevelopment of Casey House, incorporating the new Day Health Program with its existing programs, will establish a centre of excellence for HIV/AIDS clinical care, education and research. It will successfully eliminate gaps in care and better target the use of health services by Casey House clients to reduce the overall burden of care. Most importantly, it will improve the health and quality of life of the people who are most deeply affected by HIV/AIDS in our city.

With the Day Health Program as its centrepiece, the new Casey House will provide an expanded continuum of health care services for clients beyond the current range of available services. The end results will allow Casey House to provide the right care in the right place (i.e. in-patient care at Casey House, in-home care, or ambulatory care at the Day Health Program) at the right time by the right provider.

For some patients with HIV/AIDS that we see at Casey House, the residential program is the most appropriate option to provide the comprehensive care that they need. However, many others do not need that level of intense care.

The Casey House Day Health Program will provide clients who live in the community with a place where they can connect with their health care team less formally to receive clinical care, ask a question or simply share a meal with others.

Overall, the new program strengthens the partnership we have with our clients and the community.

If we can help more people living with HIV/AIDS to take agency over their health care needs, we can help them stay healthier longer and, ideally, have shorter stays at a hospital or the residential program—and perhaps even avoid them altogether.

Amy MacKinnon, RN, Casey House

## CONCLUSION

# Casey House leads the way once again: An innovative answer to the urgent HIV/AIDS crisis in Toronto

There is growing need for more innovative and responsive health care services like the Casey House Day Health Program.

Gaps exist in the system today for people living with HIV/AIDS. A 2008 needs assessment report conducted for Casey House concluded that a Day Health Program could address important unmet and under-served health needs of people living with HIV/AIDS in Toronto, particularly for individuals who are at significant risk related to social determinants of health. It recommended that the Casey House Day Health Program focus on the following social determinants that can influence health: poverty, education, housing, adequate income support, safe and secure housing, alcohol or substance use, discrimination, and access to health, social and addictions services.<sup>9</sup>

Ontario's health care system is increasingly affected by the expanding chronic care needs of an aging population. There is a deep need for programs that will allow people living with HIV/AIDS to have better and healthier lives, receiving care that is more responsive to their needs while allowing them to remain safely in their homes and out of hospital or long-term care.

A recent Ipsos-Reid survey<sup>4</sup> makes it clear that Ontarians believe that people living with HIV/AIDS deserve the best care possible. They also want this care to be provided in the most appropriate environment, using innovative models that alleviate strain on the health system.

The demands of the still-growing and unstable HIV/AIDS epidemic on the Ontario health care system are profound, and are projected to continue well into the future. Further, the clients served by Casey House often present unique challenges to health care providers due to their complexity, diversity and frequent marginalization.

Innovative approaches to care that keep people healthy and out of hospital while preserving their dignity and quality of life are absolutely essential, for the well-being of the individual as well as for appropriate use of Ontario's health care resources.

Fife House has worked with Casey House in partnership for several years and is excited to continue to work with Casey House and other community partners as the new Day Health Program is created.

The Day Health Program will be an important service. Its integrated model of clinical care along with community partner services will support our residents and clients to maintain or improve their health status, enhance their quality of life, and build on their individual strengths while promoting independence.

Keith Hambly, Executive Director,  
Fife House

As the world cries out for a global cure for HIV/AIDS, 18,000 people in Toronto are today living with the reality of what has become a profoundly challenging chronic disease, with health care needs that will increase in complexity as they age.

And their numbers continue to grow.

It is clear that the need for a nimble and adaptive response to these ongoing health care needs will continue well into the future.

Casey House and its community of support brings the experience, the ability, the drive and the passion to continue its founders' vision of excellent and compassionate health care for people living with HIV/AIDS today, tomorrow... and for decades to come.

The Casey House Day Health Program marks the next step in the evolution of Ontario's ongoing response to the urban health care crisis of HIV/AIDS.

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