



FRIENDS OF THE **camh** ARCHIVES

# NEWSLETTER

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## *The Quiet and Complicated Story of Mental Health Palliative Care*

*by Fiona L. Kenney, Doctoral candidate – School of Architecture, McGill University, Montreal*

*Friends of the CAMH Archives' Griffin Archival Research Award – 2022, and Hewton Archival Research Award – 2023*

“Because the system of care is innovative, the design is innovative, too,” wrote Lo-Yi Chan, architect of the first modern hospice in the United States, in 1971. The purpose-built hospices of the 1970s, at the birth of the modern hospice movement, demonstrate the capacity of architecture to co-develop a philosophy of care. These designs also served the important function of making palatable a setting that, before this time, had been frightening and unfamiliar to the general public.

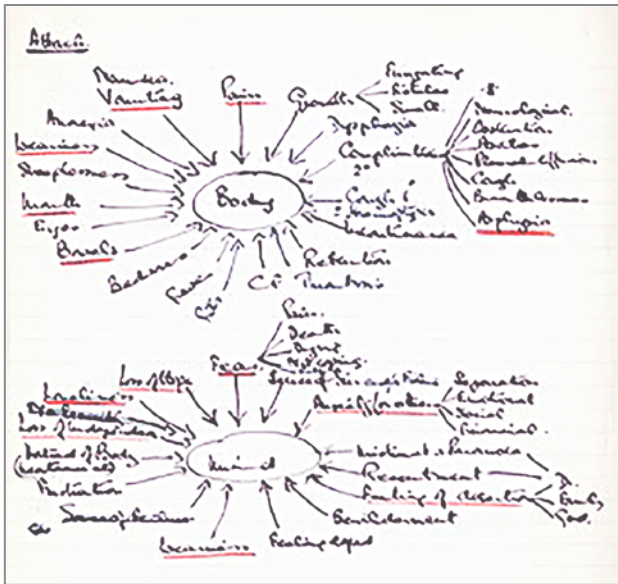
At the same time, similar sentiments were being expressed about changing mental health architectures and attitudes.

Scholars studying the 1972-4 transition of the Queen Street Mental Health Centre observed that “the erection of the new buildings served as a catalyst for the launching of new treatment programmes and the extensive reassessment of existing modalities of care. On the other hand, the buildings had been planned with specific new treatment philosophies in mind.” Once the centre was moved from a five-story, three-winged hospital opened (as an asylum) in 1850 and a 1956 administrative building, to the new, much larger treatment complex, the environment became “a concrete embodiment of the treatment philosophies and policies which guided



*The Village, Langley BC. (By permission)*

*(continued)*



Cicely Saunders' notes from patient observation at St. Joseph's Hospice

its planning.” The architecture would become “tangible settings for the introduction of new and revised treatment modalities and organized procedures.”

Though palliative care is a term coined relatively recently, specialized care for relief of symptoms in terminal patients is of course not a recent concept. The modern hospice movement, as a philosophy of care focusing on ‘total pain’ and the needs of family members, only came to be in the late 1960s, with Canadian urologist Dr. Balfour Mount coining the term ‘palliative care’ in 1973. This was roughly the same time it emerged in the US, but slightly after its emergence in the UK at St. Christopher’s Hospice. The movement’s tightly synchronized evolution across the English-speaking Western world can be partially attributed to the close relationships between key players in each location. A central few included: Mount in Canada; Elizabeth Kübler-Ross and Florence & Henry Wald in the US; and Dame Cicely Saunders in England.

In Canada and these countries, palliative care developed in relation to the “rapid expansion of cancer treatment programs in the 1970’s whereby treatment was defined as either curative or palliative,” foreshadowing the profound connection between palliative care and cancer that is still sustained today. Those today with non-cancer terminal illness, however, experience under-admittance to hospice programs, due to a disproportionate focus on cancer care’s association with ‘tragic’ or ‘untimely’ death. As such, rooms in hospital palliative care units are often visually indistinguishable from rooms for oncology patients. Palliative care is still often “camouflaged as an extension of oncology.” In the world of hospice architecture scholarship, the UK’s ‘Maggie’s Centres,’ founded by artist and writer Maggie Keswick Jencks and her husband, architect Charles Jencks, are discussed in the context of purpose-built hospices, yet are drop-in centres for individuals affected by cancer.

One of the ways the palliative care philosophy differed

from other, longer standing philosophies of care was in its concept of total pain. Championed by Cicely Saunders, recognized as the founder of modern hospice care, ‘total pain’ included end-of-life patients’ mental and spiritual suffering in addition to physical symptoms. Concerns about mental health are ‘baked in’ to the hospice philosophy. But aside from supporting patients through feelings of fear, loneliness, or confusion, the range of mental health comorbidities at end of life require incredibly specific responses, and thus are difficult to address in palliative care settings – and at least equally difficult to design for.

In the last 15 years, a trend has emerged to create memory care units for people living with dementia less like hospitals or typical mental health facilities, while more like homes. Designers have begun to employ what Annmarie Adams and Sally Chivers call the “village trope,” using pedestrian-centered public space – an emphasis on communal spaces, and central, small businesses to convey an image of “pre-industrial small towns.” Residents live in townhouses shared by small groups with similar lifestyles and interests.

Copious variations of dementia villages now exist. The first opened in the Netherlands in 2009, while Canada’s first opened in Langley, BC in 2019 (illustrated here). They are “purposefully anti-medical”: the architecture of assisted living is ‘disguised’ as a village. Medical and care staff may be disguised as post office clerks, grocery store cashiers, or servers in the town pub. These villages are controversial: some have argued that they can increase the stigmatization of dementia in society; that they can make the situation more difficult on family members visiting their loved ones in the dementia village; and that the deception may take advantage of the residents’ cognitive decline.

The architecture of mental health palliative care is dually alienated: once given the historical roots in and ongoing focus of palliative care on cancer, and again given the challenges inherent to designing for the cognitive conditions most often seen in older age. The dementia village is seen by many as an innovative care model and architecture – but still is not fixed on providing palliative care, which requires specialist equipment, staff, and other resources. An innovative architecture is needed for the



De Hogeweyk, Netherlands, 2009

provision of mental health palliative care, which would need to be developed in tandem with an innovative model of care, like the respective developments of palliative care and mental health care models of the 1970s. A thoughtful, innovative architecture can ease users and the general public into a new way of understanding illness and care. Just as the architecture of the new, 1970s Queen Street Mental Health Centre was “a symbolic focus for fundamental re-orientations in attitude,” there is a historically proven need for an architectural approach that would centre the overlap of palliative and mental health care.

Author Fiona Kenney



*(Citations available by request)*

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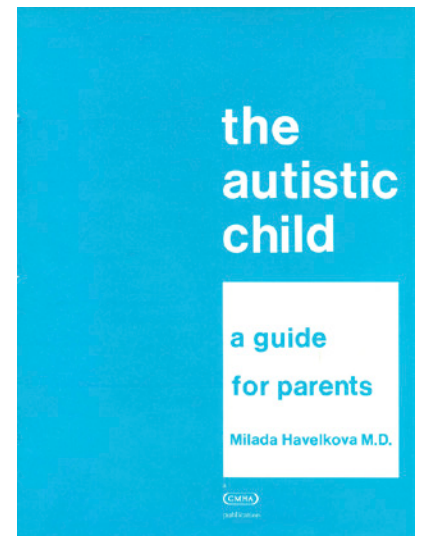
## *Historical Aspects of Canadian Clinical Intervention for Understanding Autism*

*Stacey Easton, Doctoral candidate – Graduate Program in Critical Disability Studies, York University, Toronto*

*Friends of the CAMH Archives’ Griffin Archival Research Award – 2023*

As the recipient of the 2023 Griffin Archival Research Award, I have started working on understanding the work of Milda Havelkova. Born in 1918 in Czechia, Havelkova died in Toronto, 2005. Her training at first was in traditional medical schools in Prague, but was interrupted by the Second World War. The rest of her training was completed by the equivalent to interning with an orthopaedic surgeon. In 1952 she moved to Canada with her six-year-old son. After time in Sudbury, she moved to Toronto and became a paediatric psychiatrist. The Ontario College of Physicians listed her

license as active until just a few years before her death, although her most significant work seemed to occur from the late 1950s to the early 1970s. There doesn’t appear to be significant publications for most of her career. That said, I think that her work in the beginning part of her career is vital and has been under-



*Dr Havelkova’s pamphlet cover, courtesy CMHA*



*Dr. Milada Havelkova, courtesy KanArt Gallery*

considered. This is especially true of the work she did for the West End Creche, for SickKids, and for the Canadian Mental Health Association, especially about Autism. The West End Creche, founded in 1909, had resources for Autistic children from the 1930s, but those services did not consider Autistic people as adults, and were limited by funding and geography. Havelkova’s work, beginning in the West End Creche, was to refocus care, if not on Autistic children themselves then

at least on the families that might have been affected.

This work resulted in a handful of publications, two for medical journals, but the one I was most interested in was a pamphlet written for the Canadian Mental Health Association in 1966, *The Autistic Child: A Guide for Parents*. I hadn't been able to find a copy.

I emailed back and forth with the archivist at SickKids – which might be confidential, so I won't quote it verbatim. He noted that psychiatric history is not taken seriously – that the shame/ stigma of mental illness is still strong. I also think that children's history is not taken seriously, that they are still not considered people. Therefore, to do mad people's history and children's history together, in a space where healthcare is deeply underfunded, requires an odd collection of skills. Part of the skill is cobbling together the archives, noting where gaps exist, and trying to cobble together a single narrative; part of the skill is peeling back what other people wrote about Autistic children in order to see if there is any remnant of their own lives and experiences. Considering much of this work is not ordered, or that it is hidden in other people's records, or that if it is not digitized, figuring out exactly what is there has been a trick – made more slippery by the Covid lockdowns.

The Archivist at SickKids, David Wencer, noted in his first emails that he didn't have a copy of the pamphlet, and that the archives of Dr. Havelkova had been spread – that there might be some material in the fonds about the Creche in the Archives of Ontario, that there might be some general history of psychiatry at CAMH (she did some work for the Clarke Institute), and there might be some documents kept with the Toronto District School Board. He went looking and noticed that there was a 16 mm film strip – previously undocumented – about Autism, created by Havelkova. I asked Wencer if he had a projector, and if he or someone else knew how to operate it. When looking for the projector, he noticed a pile of uncatalogued ephemera and, looking through that material, he found a copy of the pamphlet (illustrated here) – more modest than I anticipated, but chic in that Canadian post-Confederation way.

A few days later, Wencer found a couple of other documents, in addition to the film and the 1966 pamphlet, including a typescript of an interview from when she retired, and a mention that she had written another pamphlet called *The Psychotic Child in School: A Handbook for Teachers*, published in 1969 under the auspices of the Toronto District School



Author Steacy Easton – photo by Dirtfoot.

Board (the Board does not have a copy of the document), co-authored by Pearl Isabelle.

The typescript suggested other roads for research – that she possibly worked as a consultant at Bruce Grey in Owen Sound, and some discussion about how unhappy she was as a doctor, the connections between the neurological and what was at the time a more psychoanalytic mode – the answers she gives are terse, and her collected work is terse – but her pragmatism, her commitment to writing for parents, and her discussion of Autism as a biomedical model which should be intervened with, are at the crossroads of a major shift in the mode's clinical understanding.

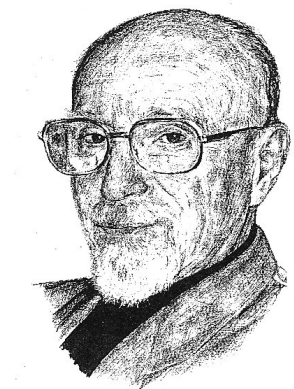
There is more research to be done. I need to negotiate access to SickKids to see the filmstrip, at the very least,

but I also need to chase other threads: the work in the CAMH Archives, where a new archivist is in process of being onboarded; and there is some discussion of the material being difficult to find, or not digitized, mirroring the similar problem of material being lost within the collections, or the better ordered collections of the West End Creche in the Ontario Archives (located at York University's Keele campus).

For someone who is Autistic, the historical mode comes through the clinical record via documents directed to families, and not through actual Autistic people. Often it seems that the family talks to the clinician, and vice versa, cutting the client out of understanding who they are as a person. Notwithstanding how terse is the material from Havelkova, when she is asked what are the lessons she has learned from her practice, she says: "Take seriously what patients and relatives say. They often know more than you do." That she foregrounds patients; that she seeks to take us seriously; and that she acknowledges the lived experience of people on the Spectrum as valid data – as early as she does – is a model worth emulating and investigating.

*(Citations available by request)*

## *Publications by the late Prof. Cyril Greenland A Bibliography-in-progress by Philip Kuhn*



*Pencil portrait of Cyril Greenland, 1998, by Irma Coucill, courtesy of the artist and Robert Davies Multimedia Publishing Inc.*

In 2012, we bid farewell to a stalwart champion of the histories of mental health and addiction with the sad passing of Cyril Greenland, Professor Emeritus of McMaster University, on New Years Day in his 93rd year. In this Newsletter's Spring, 2012 edition we chronicled our perspective on Cyril's remarkable life and contributions for our field.

Philip Kuhn, one of Cyril's many distinguished friends—colleagues and longstanding supporter of the FoCA, has thoughtfully made available via the FoCA the initial draft of his bibliography of Cyril's extensive publications. Philip has thoughtfully noted in this regard:-

“Although I crossed swords with Cyril on a number of occasions and even wrote about it in my paper on 'Reappraising the Bruce letter,' I still recognise that he was and probably still is an important figure in and for CAMH and the FoCA. Hence this is by way of a small gift for you and your colleagues - a thank you - and a token of my appreciation for all the help you have offered me to date.”

If you would like to peruse Philip's thoughtful bibliographic offering, please do let us know by email: [friendsofthecamharchives@gmail.com](mailto:friendsofthecamharchives@gmail.com)

## NOTICE OF ANNUAL GENERAL MEETING (AGM)

To Be Held VIRTUALLY  
Wednesday, May 24 2023

NOTICE is hereby given that the 33rd Annual General Meeting of the Friends of the CAMH Archives will be held remotely, rather than in-person on Wed., May 24, 2023 at 6:00 p.m.

All those interested are cordially invited to attend virtually, although only those having subscribed via current membership may participate in motions and voting.

Please register in advance: [friendsofthecamharchives@gmail.com](mailto:friendsofthecamharchives@gmail.com)

*Further details for connecting virtually will follow in due course.*

## Hewton and Griffin Funding Award Grants for Supporting Archival Research in 2024

The Friends of the CAMH Archives (FoCA), dedicated to the history of Canadian psychiatry, mental health and addiction, have established two endowment funds. These endowments annually provide funding in memory of their late colleagues, Ms. E.M. (Lil) Hewton and Dr. John D.M. Griffin, OC.

These funding awards will provide financial assistance to students, and others not necessarily associated with an academic institution, who propose to undertake archival research on an aspect of the history of mental health, including addiction, in Canada. The FoCA Board may at its discretion approve awards to a maximum of \$5,000 each.

There is no application form. Candidates are invited to submit a letter of intent, not exceeding 500 words, together with a budget and résumé, not later than November 30, 2023. These research awards are conditional on the recipients agreeing to submit progress reports within one year, and a final report including a financial synopsis within two years of receiving their financial allocation.

For examples of the archival research projects previously awarded (formerly “Bursaries”), please refer to that feature as included in the SPRING editions of our past years’ Newsletters, indexed at: <https://www.camh.ca/en/health-info/camh-library/camh-archives/friends-of-the-archives>

To apply for a 2024 award, please submit an application by the November 30, 2023 deadline, preferably via e-mail, to: [friendsofthecamharchives@gmail.com](mailto:friendsofthecamharchives@gmail.com)

Or by surface mail:

Sandhya Patel – President, Friends of the Archives, (FoCA), 1001 Queen Street West, Toronto, Ontario M6J 1H4



Lucy Strang and Ethel Turtle, Community Mental Health staff, Sioux Lookout Project at Pikangikum First Nation, 1970s - CAMH Archives

### Friends of the CAMH Archives (FoCA)

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[friendsofthecamharchives@gmail.com](mailto:friendsofthecamharchives@gmail.com)

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## Membership Renewal Notice for 2023

*New & renewal memberships and donations are preferred via our safe, secure, online partner:*



[www.canadahelps.org](http://www.canadahelps.org) or by surface mail

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\* Membership: \$30.00 or \$25.00 for students & seniors, on a calendar year basis (currently valid through Dec. 31, 2023)

\* Donation: \$ \_\_\_\_\_ (optional, at your discretion) Total: \$ \_\_\_\_\_

*\* An Income Tax receipt will be provided for your membership remittance plus any additional donation.*

*Please consider remitting online or, alternatively, by mailing this form together with a cheque, payable to “Friends of the CAMH Archives”  
Surface mailing address: Friends of the CAMH Archives, 1001 Queen Street West, Toronto, Ontario M6J 1H4*