

# H o s p i c e

# Affirming

# Life



**A Sanctuary for Palliative Care and Bereavement**

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## A B S T R A C T

The project is the design of a free standing community hospice in Victoria, British Columbia. Hospice has been called the greatest citizen initiated change in health care delivery in North American History.<sup>1</sup> Its popularity reflects a paradigm shift from that of 'experts' treating ill 'victims' to patient-centred care. In 1974, there was one hospice program in America and by 1985 there were 1500. The project is informed by an understanding of the dichotomy of life-threatening illness as a time for introspection and reflection and the potential for renewal (if not recovery) and *living until death*.

Initial investigations dealt with three main areas: 1. The historic roots of the hospice movement and tenets of hospice philosophy; 2. The experience of life-threatening illness, and objectification of the ill, reducing them to objects of pathological investigations and treatment of disease. The sociological and cultural aspects of stigmatization and objectification are examined; 3. A precedent study of free standing hospices, including the first North American facility in New Haven, Connecticut.

The aim of the project is to create a sanctuary within the vibrant urban core. The inner-city site was selected for its interface with nature as well as culture. It borders Beacon Hill Park (154 acres) to the south and the historic St. Ann's Academy site (6 acres) to the north.

The sloping site is one means of layering the public and private realms of the project. The ground level on Academy Close houses an outdoor urban courtyard, a cafe, poetry and fiction reading room, resource room, conference, staff and volunteer offices. This level also houses day and evening programs for ill people, caregivers and the bereaved. The upper (park) level houses the most private component of the hospice — the residence. It contains seven private studio apartments, common areas and a light box.

Key design explorations are: The creation of a sanctuary within a vibrant urban area, the re-interpretation of the retaining wall as a spine grounding and anchoring the building, layering of space and architectural boundaries. The project aims to contribute to a better understanding of the experience of life-threatening illness, engendering an architecture that translates this understanding sensitively and creatively.

<sup>1</sup>Hudson, 1988. *The Hospice Response to Contemporary Western Attitudes on Death and Dying*

### K E Y W O R D S

hospice, palliative care, sanctuary, Victoria, community, isolation, belonging, continuum, duality

## A C K N O W L E D G E M E N T S

I wish to extend my appreciation to the members of my committee: Loraine Dearstyne Fowlow, Leslie Tutty, Brian Rusted and Michael McMordie for their input and support.

Thank you to the staff at the hospices I toured, to Tyleen Katz of May's Place, Vancouver, to staff and fellow volunteers at Victoria Hospice. Discussions with Arthur Frank (Sociology) contributed to my depth of understanding of the experience of life-threatening illness. Edna McHutchion (Nursing), President of the Canadian Palliative Care Association offered her keen insight and reviewed the work in progress.

Thanks also to all of my friends and relations who offered support in realizing a dream. Special thanks to Bruce for his love and partnership in life's journey.

This project is dedicated to Owen, Noel and Meadow and to my mother and father.

## **C O N T E N T S**

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Modern medicine focuses on acute care, cure and recovery and in many areas it excels. In this context death may be perceived as a failure. While death is a failure to achieve the goal of saving lives and achieving recovery, it is also the inevitable conclusion to each and every life.

The modern hospice movement has developed as a response to the need for care where recovery is unlikely. Its focus is palliative care, namely the provision of services oriented toward comfort rather than cure. Palliative care usually begins where active treatment ends.

The aim of hospice and palliative care is to attend to the whole person, rather than to treat a disease. Hospice is concerned with quality of life rather than recovery, in the usual sense of the word.

“If recovery is taken to be the ideal, how is it possible to find value in the experience of an illness that either lingers on as chronic or ends in death? The answer seems to be in focusing less on recovery and more on renewal. Even continuing illness and dying contain opportunities for renewal”!

Hospice philosophy recognizes that the physical issues of life-threatening illness need to be addressed. These often revolve around pain control, symptom management and comfort.

Yet in hospice philosophy, care goes beyond the physical or profane aspects, beyond illness to the experience of the person. Social, emotional and spiritual needs are respected, along with physical needs.

## Palliative

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Hospice philosophy honours the journey at the end of life as profound. The paradox that sacredness may be found in the everyday is one well known to those in the field of palliative care.<sup>2</sup>

In considering the design of a hospice facility, many factors should be considered. The design should address physical needs for comfort and security. Hospice seeks to treat death as a normal experience. This is appropriate in the sense that it is normal that people die. However, in the context of one's life, death is not an ordinary experience. For this reason, the design of a hospice should touch on deeper meaning, inspiration and ritual appropriate to the significance of the journey at life's end.

It is impossible to embark on a project that addresses illness and dying without engaging in contemplation and reflection.

As I visited the hospices chosen for the precedent study, I found myself wondering what kind of place would I choose if given a prognosis of life-threatening illness — at my home, as most people choose. But what if that was not possible at some time? This questioning and the stories of those I have spent time with at hospices, along with some of architect Steven Holl's work, led me to the question: "What is this hospice place?" Is its essence poetic, physical, sacred or profane? Is it a place of stories, a gathering of lights, a residence, a cloister, a community, a guest house, a hospital, a place of living, a place of dying?

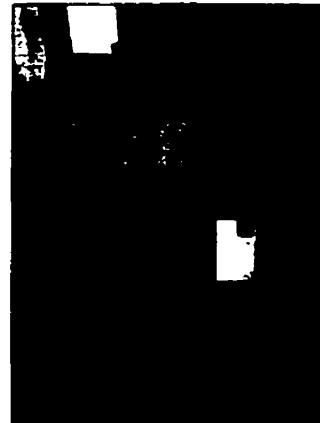
One source of information is history — to know the roots of this movement. Another is to understand how medicine in this century has changed the face of death and led to a rebirth of hospices.

Other sources of information are the stories and experiences of those facing life-threatening illness and loss.

In 1994, I completed a hospice volunteer training program and later took advanced spiritual and emotional support courses.

## What is

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I have been privileged to spend time with many ill people, some of them in the final stages of dying. I have heard sad stories and terrible stories and funny stories and angry stories and healing stories. I have given reiki and foot-rubs. Together, we have gone for walks, watched TV, shared home-made apple pie, jokes and stories and been silent.

I have spent time with friends and family members, both before and after their loved one's death. I have volunteered with walking groups for bereaved adults, support groups and a summer camp for bereaved children. I have received more than I have given, and all of this informs the project.



## Endnotes

1. Frank, Arthur, 1991.
2. See Callanan, Maggie and Kelley, Patricia (1997), Remen, Rachel Naomi (1996) and Kubler-Ross, Elisabeth (1969) for stories about healing, reconciliation and spiritual experiences during life-threatening illness and close to death. It is not uncommon for anecdotal stories of this nature to be told by hospice staff members and volunteers.



what if the soul is here for its own joy — for the pure sake of experience

what if the soul doesn't care about efforts at immortality  
about leaving legacies, about the accumulation of wealth  
about leaving property, possessions and published works

what if the soul is longing for the sound of fall leaves  
crunching beneath your feet, for spontaneous dances  
and poems  
and silly songs

what if longing is the voice of the soul  
saying  
'what about me' ...

what if the soul is here  
simply  
to love you

This chapter will explore hospice in its historic and modern context. It examines the philosophy of hospice care and provision of services.

### History

Hospitality, hospital, hostel, hotel, host, and hostess share the same Latin roots. *Hospes* means both guest and host, perhaps implying a process of human interaction or mutual exchange. *Hospitium* refers to hospitality, refreshment, fellowship and cherishing.<sup>1</sup>

Ancient hospices and hospitals provided sanctuary for the sick and dying, women giving birth, orphans, the needy and religious pilgrims.

Hospices developed in main towns along routes to Rome and the Holy Land. They accommodated travellers and also served the sick, the wounded and the dying.

One of the earliest known western hospices was founded in 390 AD in the port of Rome by Fabiola, a disciple of St. Jerome. Her intent was to care for pilgrims returning from Africa.

For many centuries, hospices and hospitals and hotel-Dieu were interchangeable, providing refuge to the traveller, the ill and the dying. This reflected a view of life as a journey or sojourn toward some future state of rest and blessedness.<sup>2</sup>

From the fifth century onward, hospices were largely run by monastic orders. In the medieval world view, life and death

### Hospes

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were seen as part of the same mortal process. Travellers were valued for their insights and news of the outside world. The dying were regarded as individuals on the road to a higher plane of existence.

By the 12th century, the church was establishing hospitals proper. While care of the dying was not the distinctive function of hospices, the dying were not turned away.<sup>3</sup>

The Reformation saw the closure of monasteries in many countries. The influence of the church on medicine declined and religious hospices and hospitals gave way to civic hospitals, workhouses and charity wards.<sup>4</sup>

After the Reformation, the spirit of hospice was continued in the work of social reformers such as St. Vincent de Paul. He founded the Sisters of Charity in 17th century France to care for orphans, the poor, the sick and the dying.

In the 18th century, a Prussian baron visited the Sisters' houses in France and encouraged the establishment of a Protestant hospice upon his return. The French and German sisters provided training for Irish and English visitors.

In the 1850s, Mary Aikenhead founded the Irish Sisters of Charity and opened St. Vincent's Hospital in Dublin. The Irish sisters established Our Lady's Hospice at Harold's Cross near Dublin in 1879.

Sisters of Charity opened St. Joseph's Hospice in London in 1905. Its emphasis on comfort rather than cure inspired Dr. Cicely Saunders. In the 1950s and 1960s, she refined her understanding of terminal cancer pain control at St. Joseph's. She later became famous for her pioneering work in the hospice movement.

### **Western Medicine and Acute Care**

The current western medical system is oriented toward investigation, diagnosis and cure. Healing is defined as recovery and the goal is curative.

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The 15th century view of western medical care was broader in definition: it was to cure sometimes, to relieve often and to comfort always.



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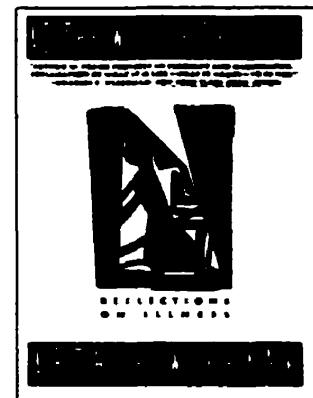
In modern times, the field of medical ethics has emerged in response to the complexities surrounding physicians' responsibilities. Acute care has been criticized for focusing on the disease rather than the person. Michel Foucault traces the shift from emphasis on the patient to emphasis on the affliction to the birth of the modern clinic in 18th century Europe.<sup>5</sup> The acute care hospital is seen as a descendant of the late 18th century European medical clinic, having the primary function of delivering technology as effectively and efficiently as possible.

Sociologist Arthur Frank argues for the need to shift the focus of care away from the illness to the experience of the person. He explores the negative and dehumanizing effects of isolating the affliction from the experience of the human being with the illness.<sup>6</sup>

One of the effects of separating the illness from the person is that the complex emotional and thinking being is reduced to an abnormal affliction. It is not only medical staff who may view the ill person this way; family, friends and the ill person may begin to focus primarily on the status of the illness. This can create tremendous feelings of isolation.

In recent decades, the modern western medical model has come under attack quite specifically for its lack of concern and compassion for the dying. With its focus on affliction, investigation and cure, it has been criticized for abandoning those with terminal diagnoses.

The death with dignity movement, fostered by Elisabeth Kubler-Ross and proponents of palliative care, directed strong criticism at acute medicine. They questioned the focus on affliction rather than people and the view of healing based on recovery of physical functioning versus concern for quality of life.



## Sociologist

Arthur Frank argues for the need to shift the focus of care away from the illness to the experience of the person. He explores the negative and dehumanizing effects of isolating the affliction from the experience of the human being with the illness.

The 1969 publication *On Death and Dying* by Kubler-Ross was one of the early popular books to question the treatment of the terminally ill in hospitals. It addressed the need to “refocus on the patient as a human being, to include him in dialogues, to learn from him the strengths and weaknesses of our hospital management of the patient.”<sup>7</sup>

In a more recent bestseller, surgeon Sherwin Nuland writes: “Even with all its art and philosophy, the modern profession of medicine has become, to a great extent, an exercise in applied science, with the goal of conquest in mind. The ultimate aim of the scientist is ... the aim of overcoming that in our environment which he views as hostile. None of the acts of nature is more hostile than death. Every time a patient dies, his doctor is reminded that his own and mankind’s control over natural forces is limited and will always remain so ... Medicine’s humility in the face of nature’s power has been lost ...”<sup>8</sup> Along with others, Nuland questions whether medical technology is being used to deny impending death at the cost of delivering humane care at the end of life.

By focusing on technology, doctors are able to distance themselves from the suffering faces of other human beings.<sup>9</sup> This is not only true of doctors, but of ill people and their loved ones. The focus of attention can easily shift to the disease. We risk losing the voice of the living person, reducing the story of their experience to a medical one.

Western culture is often labelled as death-denying, expressing the view that reluctance to deal with death is culturally pervasive.<sup>10</sup>

“In our society death is viewed as a failure, a catastrophe, or an unnatural or immoral act from which we should be shielded. This attitude is an expected response to our medical technological ‘progress.’ The dying process can now be extended; it is increasingly mechanical and fearfully dehumanizing. But instead of working to combat fears through education, most physicians tend to reinforce and promote them by refusing to accept the fact that there is a time to die.”<sup>11</sup>

## None of

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Sherwin Nuland,  
surgeon

A 1997 survey by American Health Decisions, a coalition of citizen groups concerned about ethical issues in dying, found that Americans were more afraid of dying than of death. They conducted a survey of 385 people, interviewed in 36 focus groups. They found that many Americans fear dying alone, hooked up to machines.<sup>12</sup>

### Contemporary Palliative Care

In the 1960s, Kubler-Ross drew attention to the problems caused by a medical system unprepared to deal with the dying. She offered a view of dying as a final stage of growth, rather than as a failure to be cured.

Cicely Saunders also brought attention to the need for care of the dying. She is considered the founder of the modern hospice movement, having established St. Christopher's hospice in London, England in 1967.

The increased interest in quality of life for those faced with life-threatening illness and their loved ones has led to the development of care that is oriented toward comfort rather than cure. This type of care addresses more than physical care. Commonly known as palliative care, it is primarily concerned with enhancing quality of life for people facing life-threatening illness. Palliative care includes not only symptom management, but everything that is done to assist the ill person with living.

In Canada, palliative care began largely as an institutional phenomenon. Palliative care units were set up within existing acute or chronic care hospitals. Some of the reasons for this were to avoid the expense of creating new buildings and to access hospital staff and facilities.<sup>13</sup>

In Canada the term 'palliative care' is often used instead of the term 'hospice', although both are common. This is because of an association of the word 'hospice' with an alms house, or poor house in French Canada.



The Latin *palliatus* means dressed in a cloak. Cloaking the discomforting symptoms of dying is not solely the focus of palliative care. "It is a philosophy in which the patient is treated as a person, not a mere vessel for disease."<sup>14</sup>

### Hospice Philosophy

Early hospice literature sings the praises of a much needed reform movement, emphasizing the need for compassionate, humanistic and respectful care for the dying. Hospice is considered first and foremost a philosophy of care. "Hospice is an attitude toward life and toward death; it is an attitude of caring, of personal treatment that values the human spirit and sees each human being as worthy of love and care, regardless of age or physical condition. Hospice sees the patient as both giver and receiver. Hospice is more than a building, although buildings help facilitate hospice services. Hospice is a philosophy and practise of care."<sup>15</sup>

This notion of patient as giver and receiver is reminiscent of the root word *hospes*, meaning both host and guest.

Hospice philosophy is concerned with quality of life for as long as life lasts. It seeks to create opportunities for compassion and choice so that people with life threatening illness can live as fully as possible and die as peacefully as possible.

The American National Hospice Association defines hospice philosophy:

"Hospice affirms life. Hospice exists to provide support and care for persons in the last phases of incurable disease so that they might live as fully and comfortably as possible. Hospice recognizes dying as a normal process whether or not resulting from disease. Hospice exists in the hope and belief that, through appropriate care and promotion of a caring community sensitive to their needs, patients and family may be free to attain the degree of mental and spiritual preparation for death that is satisfactory to them."<sup>16</sup>

## Hospice

**affirms life. Hospice exists to provide support and care for persons in the last phases of incurable disease so that they might live as fully and comfortably as possible.**



Hospice care seeks to eliminate suffering in the dying process. I have heard patients recount stories of doctors who refused to believe they were in pain. One woman described how she had been accused of fabricating pain in order to be given drugs. Her reply was "there are lots of easier ways to get drugs if I wanted them". She felt tremendously relieved that hospice staff took her accounts of pain seriously.

The current debate on the legal use of marijuana for cancer symptoms is based on the desire for better pain management.

One of the principles of hospice is that care is patient-centred and considers the experience of ill persons and their loved ones as integral to all aspects of decision making.

"Historically — since the industrial revolution — dying has been a coming-apart experience for most families. Hospice care concentrates on making the process of dying a coming together experience for patient and family. Hospice is not a place or an institution but a philosophy of care in which the person is considered of primary importance and the disease is secondary."<sup>17</sup>

### **Hospice care**

The John D. Thompson Hospice Institute offers the following definition of hospice care:

"... a specialized health care program focusing on symptom control, pain management, psycho-social support and spiritual care for patients and families living between the onset of a life-threatening condition and the end of life. Hospice care is interdisciplinary in nature and promotes patient and family participation in choosing options that will provide the most dignity, hope and comfort."<sup>18</sup>

In order to support the philosophy that hospice care should allow people facing life-threatening illness to live as fully as possible until death, a variety of services is provided.

### **Historically**

— since the industrial revolution — dying has been a coming-apart experience for most families. Hospice care concentrates on making the process of dying a coming together experience for patient and family.

The basic concepts of hospice care are:

- patient-centred care
- multi-disciplinary team approach
- pain control and symptom management of physical, emotional, mental and spiritual discomfort
- medical accessibility
- home care
- training of loved ones as care givers
- utilization of volunteers
- bereavement programs

Patient-centred care refers to a framework of asking what is best for the patient and their loved ones, considering the individual's physical, emotional and spiritual needs. The patient is not only the object of these discussions, but included in them. Where there are conflicts, the patient's choice takes precedence. The convenience of the staff providing services is secondary. For example, if a patient wishes to refuse pain medication for the sake of alertness, this is respected even if it is harder on the staff and loved ones.

The multi-disciplinary team approach refers to both the team concept and to the composition of the team. In order to meet the mandate of ministering to physical, emotional and spiritual comfort, the team usually includes doctor, nurse, counsellor and spiritual care coordinator. Other types of therapies, such as music therapy, art therapy, physiotherapy and reiki are commonly available. Volunteers are almost always part of the hospice team and their duties vary widely, for example from office work to emotional support. Most hospices have extensive volunteer training and upgrading programs.

Medical accessibility refers to availability of hospice care. The majority of hospices are not-for-profit and do not refuse people on the basis of financial need.

Home care refers to the provision of services to assist people in their own homes. A range of hospice services may be available for those remaining at home.

Again, the multi-disciplinary team approach is used and hospice services are coordinated with other agencies.

The following example from the area of pain control illustrates how the hospice philosophy influences care. The common method of dealing medically with chronic pain is to use medication PRN, *pro re natae*, "whenever necessary" at the onset of pain. In hospice care, attempts are made to mitigate pain by providing medications prior to its onset. This reduces mental and physical anguish experienced by those who are repeatedly in pain while awaiting medication or waiting for it to take effect once it is administered.

Eliminating the debilitating effects of anticipation of pain, with death as the only promise of relief, is a goal of hospice care. One man told me that prior to his wife's successful pain management she was on a four-hour cycle of medication. She was in discomfort for an hour before her medication, drowsy for two hours after her medication and alert and comfortable for the fourth hour. Yet the comfort of the fourth hour was offset by anticipation of the discomfort to follow. With a change in the method of delivery of medication, a state of comfortable alertness was maintained on a continuous level. This is a practical illustration of the hospice philosophy of improving the quality of living until you die.

"The hospice community makes every effort to provide appropriate care and to promote a caring community which is sensitive to the needs of the patients and families. It is hoped this will help them attain a degree of mental and spiritual preparedness for death."<sup>19</sup>

### **Provision of Hospice Services**

The delivery of palliative and hospice care takes place in the following ways:

- The provision of home care services
- Provision of care within a hospital
- Provision of care at a free-standing facility, meaning one that is run independently of a hospital
- Day programs

## **Eliminating**

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Most hospice services are variations on these types. For example, some hospices are located within hospitals or on hospital grounds, yet are independently funded and/or operated. Many people consider that in order to provide for choice — the foundation of hospice care — the option of care at home is essential. It is common to find hospice programs that offer a large home care component with inpatient backup for crises and/or imminent death.

The organization of hospice services varies according to the vision of its founders, the available resources and the needs of the community. Attempts are made to avoid duplication of services. In locations where home care community nursing services are in place, hospice home services are designed to complement rather than replace the existing services.

In 1974, there was one hospice program in the U.S. By 1985, there were 1,500.<sup>20</sup> Hospice has been called a counter-institution, a counter-culture, a social reform movement, a human rights movement and “the greatest citizen initiated change in health care delivery in North American history”.<sup>21</sup>

In 1985, U.S. hospices were categorized as approximately 40% hospital-based and 60% based in community programs of one kind or another, either broader home health agencies or single purpose hospice units.<sup>22</sup>

### Hospice Development and Trends

The hospice movement is undoubtedly growing and receiving increased acceptance and respect from health professionals and the public.

In the hospice movement there is general consensus that hospice programs must have a degree of autonomy in order to facilitate the quality and holistic view of care, the flexibility and choice inherent in its philosophy. In the attempt to find financial support for palliative care, there is a risk of hospice philosophy being co-opted by the established health care system which necessitated it in the first place.

## Hospice

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Beyond the scope of this thesis, but of growing concern, is the risk that hospice will be valued because it is cheaper than acute hospital care, rather than because of the humanistic values it espouses.

There is a growing sentiment that hospices will need to further develop autonomy if they are to avoid the negative aspects of institutionalization and be faithful to the philosophy of hospice care. There is also concern that hospices should develop standards for self-evaluation. The Canadian Palliative Care Association is active in the creation of standards in the field.<sup>23</sup>

Hospices within hospitals usually do not have as much flexibility as free-standing (autonomous) hospices. The absence of facilities for loved ones to stay over, lack of cooking facilities, difficulty of access to the outdoors and restrictions on visiting by children and pets are examples of limitations that may effect hospital-based palliative care programs.

Public concerns about hospice have included its historical religious affiliations with Christianity and focus on spiritual aspects of death. Many hospices avoid specific religious associations, while acknowledging that for most people death has profound spiritual meaning. It is common for hospices to have a 'Spiritual Care Coordinator' on staff.

We live in an increasingly secular society, in which medicine has largely been isolated from its earlier religious associations. Concerns that the religious background of hospice should not be imposed upon the participants in hospice programs are legitimate.

"It is no secret that the values and moral beliefs of palliative care have been strongly rooted in the Christian faith. The palliative care movement in its beginnings was a Christian protest against insensitive hospital treatment of the dying. Most palliative care programs are open to all denominations or those with no religious beliefs at all. Most palliative care providers do not attempt to proselytize ... Sometimes the religious penchant of some of those who are drawn to work with the dying slips through."<sup>24</sup>

**There is a growing sentiment that hospices will need to further develop autonomy if they are to avoid the negative aspects of institutionalization and be faithful to the philosophy of hospice care.**

Fundamental to the view of hospice as a social reform movement is its concern with a shift from poor care for the dying to a more humanistic approach that respects a person's right to make choices and live fully until death.

The question of how far hospice should go in respecting people's choices is not an easy one. At times requests are inconvenient. For example, how do we allow the burning of sweetgrass at the bedside of a native person and not set off the fire alarm? At other times ethical and legal questions arise, such as whether to let HIV drug users 'shoot-up' in a hospice setting.<sup>25</sup>

### Who Does Hospice Serve?

Mandates for the provision of palliative care vary widely. Most hospices provide care once active curative treatment has stopped, or at least stopped being the primary focus. However, there is quite a continuum of palliative care, from pain control, companionship and counselling to the provision of oxygen, IV's and "palliative radiation" to shrink tumors for pain control where hope of cure is unforeseen.

Some hospices specialize in care for certain groups, such as children, persons with AIDS, or adults diagnosed with cancer and expected to die within six months. Other hospices are open to anyone with a limited prognosis.

### Summary

It is important to understand the historical context of the hospice movement and the hospice philosophy of care.<sup>26</sup> Seeing the ill person as both host and guest respects each individual as unique and entitled to live out his or her life on their own terms. It also recognizes that relationships between staff, volunteers, family members and ill people are reciprocal, shifting the emphasis away from passivity and focus on disease.

Reflecting on hospice philosophy means continually thinking of how much quality of living is being enhanced by the program, site and design decisions.

The philosophy of care may affect the site selection in significant ways. An example is that selecting a site that is difficult to access by public transit might disempower, rather than empower, ill people and their loved ones.

Programming and design decisions may enhance or deter opportunities for privacy, comfort and control; examples are:

- residential rooms sized to accommodate friends and family
- alternatives to the conventional nurses station
- accessibility for beds as well as wheelchairs

## Reflecting

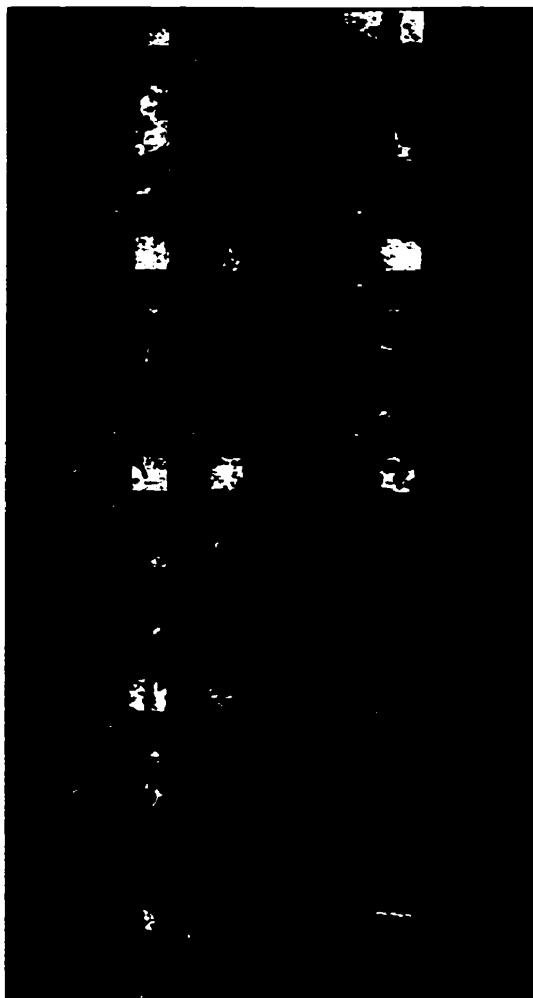
on hospice philosophy means continually thinking of how much quality of living is being enhanced by the program, site and design decisions.

## Endnotes

1. Buckingham, 1996 (p.41-43), Hudson, 1988, p. 31-35), Pevsner 1970 (p. 139-143), Stoddard, 1978 (p.3, 9-27, 39-45, 80-86, 211-213) have sections on the history of hospice and hospitals.
2. Stoddard, 1978, p.13.
3. Hudson, 1988, p.34.
4. Buckingham, 1996, p. 41- 43; Hudson, 1988, p. 34.
5. Foucault, 1973, p. 59 in Hudson, 1988, p. 95; Hudson quotes Foucault.
6. Frank, 1991.
7. Kubler Ross, 1969, Preface.
8. Nuland, 1994, p. 259.
9. Books as diverse as Simone de Beauvoir's *A Very Easy Death* and the recent bestseller, *How We Die* by Dr. Sherwin Nuland question the appropriate use of technology and the fear of death common in contemporary society. Nuland also writes of the physical distancing between physician and patient that comes with technology, tracing it to the invention of the stethoscope, which allowed the doctor to hear a patient's heart without placing his head on the patient's chest.
10. Rando, 1984. Sontag, 1990.
11. Buckingham, 1996, p. 230.
12. Lipman, Larry. (1997, October 20.) Americans More Afraid of Dying Than of Death. Cox News Service.
13. Buckingham, 1996, p. 39.
14. Mullens, 1997, p. 205.
15. Buckingham, 1996, p. 235.
16. Hudson, 1988, p. 45.
17. Buckingham, 1996, p.17.
18. No author given, (1997, August.) *Clinical Pastoral Education* Overview, John D.Thompson Hospice Institute, Brantford, Connecticut.
19. Buckingham, 1996, p. 28.
20. Hudson, 1988, p. 98.
21. Hudson, 1988, p. 42.
22. Hudson, 1988, p.38.
23. As explained by Edna McHuchion, President of the Canadian Palliative Care Association, in an informal discussion in September 1997.
24. Mullens, 1997, p. 226-227.
25. These are actual examples, the first being raised by staff at Victoria hospice and the second referred to in Mullens, 1997, p.241.
26. Edna McHuchion expressed the view that the hospice philosophy of care should be central to the design in an informal interview in September, 1997.

five year's of loss  
five years of longing  
five years of never belonging

deep in my heart  
we sit together  
at the secret cave  
drinking of life's fountain



This chapter will examine the changing face of dying in the 20th century. Aspects that may be relevant to the siting, program and design approach are considered, such as loss of control, stigmatization and isolation.

### The Changing Face of Death

The face of death has dramatically changed in this century. Many illnesses that previously threatened people at various stages of life have been largely eradicated.

Although a host of diseases unknown or un-named at the turn of the century now exist, a higher percentage of people reach old age today than ever before.<sup>1</sup> Since the turn of the century, life expectancy in both men and women has been extended by two decades. This is the largest increase in life expectancy in the history of the human race.

This change has come about for a number of reasons. In the first half of the 20th century, increased life expectancy was due primarily to improved nutrition, sanitation, immunization and antibiotics. The major life threatening illnesses of the first half of the century such as polio, tuberculosis, tetanus, rheumatic fever, pneumonia, syphilis and meningitis were brought under a significant degree of control by mid-century, although there has been a recent resurgence in some.

In the second half of the 20th century, the introduction and development of 'rescue medicine' resulted in increased longevity. In the 1950s, machines that could do the work of the heart, lungs and kidneys were improved. These technologies rescued people from the edge of death, temporarily functioning in place of organs.

### The face

of death has dramatically changed in the 20th century. Many illnesses that previously threatened people at various stages of life have been largely eradicated.



In the mid-1950s, the respirator replaced the iron lung of the late 1920s. Ventricular defibrillators were perfected and successfully employed in cases of cardiac arrest, while heart-lung bypass machines allowed the development of cardiac surgery. By the 1960s, refinements in dialysis enabled the rescue of people suffering from kidney failure.

Hospitals created intensive care units to operate and monitor increasingly sophisticated rescue equipment and to provide treatment to people on the brink of death. With the success of these life-saving measures, optimism about the potential of modern medicine soared.

It was not until the late 1960s that some people began to openly question the use of technology to fight death. In his 1969 book *Medical Power and Medical Ethics*, Dutch physician Jan Henrik van den Berg wrote critically about moral consumerism that accepts the application of technology without reflection. He questioned whether or not technology actually improved lives and argued that often, it did not.

His book was translated to English in 1978. It is a chilling account of case histories illustrating medical interventions to extend life, without apparent concern for the quality of life or prolongation of suffering such interventions may engender.

In 1961, the *Journal of the American Medical Association* reported on a study finding that 80% of doctors polled preferred not to tell patients they had cancer. At the same time, a number of studies revealed that the majority of people preferred to be informed if they had a serious illness.

Books and studies such as these fueled debate about patients' rights, medical decision-making and informed consent. The field of bioethics emerged out of the awareness that new medical technologies pose moral dilemmas. The concern with patients' rights and questioning of the application of technology happened in tandem with studies that showed that hospitalized terminally ill people were often ignored by doctors. It was as if saving lives had

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become the focus of medical care and death was the enemy rather than the conclusion of every life.

The question of what constitutes a 'good death' is increasingly raised as large numbers of people live long enough to face the possibility of chronic degenerative diseases, long illnesses and old age.

In 1994, it was reported that 80% of Americans died in hospitals. In 1949, the figure was 50%, in 1958 it reached 61% and in 1977, it was 70%. Canadian figures are similar.<sup>2</sup>

The increasing popularization of the right-to-die debate and the growing use of living wills reflect social concern for quality of life and an increasing demand for control. Advocacy for partnership between patients and care givers in medical decision-making is growing and 'medical paternalism' is being challenged.

As discussed in chapter one, the hospice movement and philosophy of care was largely a reaction to the treatment of the terminally ill in hospitals. According to hospice philosophy, the needs of ill persons and their loved ones should inform decision-making, including medical decisions.

### Choice

"A desire to be in control of our lives and the environment around us is born in each one of us ... the need for individuals to attempt to control their personal environment is an intrinsic necessity of life itself".<sup>3</sup>

The concept that individuals need to feel a sense of control over their environment has been tested and affirmed in numerous studies.

In one such study, two psychologists from Harvard and Yale universities, Langer and Rodin, tested the hypothesis that many elderly people become senile, debilitated and helpless when living in an environment that removes their personal control and decision-making.<sup>4</sup> The psychologists found that



people who feel a sense of control over their environment fare better than those who do not.

The study was conducted at a New England nursing home. Residents of similar age and with similar infirmities were selected, and divided into two groups.

With staff cooperation, Langer and Rodin set about to give the two groups different messages about the amount of control and responsibility they could exercise.

One group of residents was told that staff would make decisions for them and look after them. They were encouraged not to worry. They were given plants and told staff would tend them. They were told they could see a movie, yet staff selected the movies to be viewed and the times for viewing.

In contrast, those in a second group were encouraged to make their own choices and to lodge complaints and make suggestions about their living arrangements. Personal responsibility was stressed in decisions such as the furniture arrangements in their rooms and selecting their activities. They were asked to choose a plant they liked and encouraged to look after it. They were asked to make movie selections and decide when they wanted to view them.

Three weeks after the onset of the study, residents were questioned. The residents with more choices were found to be happier, more active and more sociable than those encouraged to feel more dependent. Eighteen months later, residents with more control still proved to be more active and happier. Their doctors rated them as being healthier and more of them were still alive. Thirty per cent of the residents whose dependence had been encouraged had died compared with 15 per cent of the group encouraged to exercise more control. These findings are consistent with other studies showing that personal control is important to health.

Personal control may shift during life-threatening illness from activity oriented control to psychological control. Examples might be the control of deciding how one's room

## A study

by psychologists Langer and Rodin found that personal control is important to health.

is laid out or the decision to be looked after and be pampered versus doing everything one possibly can, regardless of the physical and emotional effort required.

"Psychological studies show that when individuals experience feeling a loss of control one of two things happen, either they rebel or they give up and adopt positions of helplessness. ... When people experience a sudden loss of control in their personal life, one of the most common results is a feeling of depression."<sup>5</sup>

### Loss in Illness

Those with life-threatening illness are faced with multiple losses. Confronting loss of existence is impossible to imagine, yet that is what people with life-threatening illness must try to cope with. Anticipated losses may include losing all of one's relationships, one's work, the activities that bring pleasure and loss of physical abilities. Usually these losses are progressive and cumulative.

Depression, grief and strong emotions may be normal reactions to the prospect of irreversible loss. Loss of control is one of many losses an ill person may experience.

"As a society, we have come to expect the sick and dying to accept a loss of control as being a function of the dying process. Even the words we use to describe serious illness reflect this traditional expectation of powerlessness. Someone who is sick is called an invalid, meaning without force, not valid. Often we speak of people with illness as being victims of their disease, such as 'cancer victims' and 'AIDS victims'. ... We seem to expect them to acquiesce choices to the care and expertise of others. ... Even the word 'patient' as applied to individuals under medical care has traditionally implied that once entering into the medical model they are expected to bear their pain or trials without complaint."<sup>6</sup>

Resistance to giving up one's rights and choices during illness is increasing. An illustration is the insistence of AIDS activists on the use of the phrase 'persons with AIDS' or

PWAs. This is an attempt to eliminate the stigma of the passive connotation of the word 'victim'.

The opportunity to exercise choice, even as options may be diminishing, is important. Life-threatening illness is a time of mounting losses and shifting hopes and having the opportunity to exercise choice is vital to maintaining some sense of control. This does not mean every individual welcomes choice, but the opportunities should be present.<sup>7</sup>

### **Isolation and Stigma**

Other factors contributing to powerlessness, discouragement and depression among the ill are isolation and the disturbing sense of being treated as an affliction rather than as a person. In the words of sociologist Arthur Frank:

"The more critical my diagnosis became, the more reluctant physicians were to talk to me. I had trouble getting them to make eye contact; most came only to see my disease. This 'it' within the body was their field of investigation; 'I' seemed to exist beyond the horizon of their interest."<sup>8</sup>

Many authors have written about cultural attitudes toward the ill as contributing to, if not creating, increased pain and isolation for those faced with life-threatening illness.<sup>9</sup>

Susan Sontag argues eloquently that in an era in which medicine's central concern is with diseases that can be cured, life-threatening illness is not understood and therefore mysterious. She writes of the charge of stigmatization of untreatable diseases:

"It seems societies need to have one illness which becomes identified with evil, and attaches blame to its victims..."<sup>10</sup>

"... nothing is more punitive than to give a disease a meaning — that meaning invariably a moralistic one. Any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance. First, the subjects of deepest dread (corruption, decay, pollution, anomie, weakness) are identified with the disease. The disease itself becomes a metaphor."<sup>11</sup>

### **The more**

critical my diagnosis became, the more reluctant physicians were to talk to me. I had trouble getting them to make eye contact; most came only to see my disease. This 'it' within the body was their field of investigation; 'I' seemed to exist beyond the horizon of their interest.

**Arthur Frank**

In *Daybreak*, Nietzsche writes:

"Thinking about illness! — To calm the imagination of the invalid, so that at least he should not, as hitherto, have to suffer more from thinking about his illness than from the illness itself — that, I think, would be something!"<sup>12</sup>

Sontag argues that blaming the ill for their illness, self blame among the ill, and isolation result from the stigmatization of disease. According to Sontag, once the mysterious nature of a disease is resolved and it is understood and treatable, the stigma is transferred to another disease. In this manner the stigma has shifted through the years, from tuberculosis to cancer and is again shifting, this time from cancer to AIDS.

It is not uncommon for the ill and bereaved to find themselves feeling abandoned or distanced from colleagues, friends and loved ones. Over and over I have heard people facing life-threatening illness, and bereaved people, tell stories of feeling isolated.

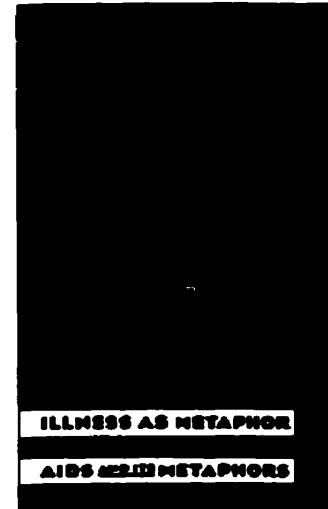
Sontag, herself a cancer survivor, notes:

"... a surprisingly large number of people with cancer find themselves being shunned by relatives and friends ..."<sup>13</sup>

All too often the ill are treated as victims, recipients or dependents with little left to give. Some people find friends and loved ones rally, at least at first, while others may find people avoiding them or pitying them. But what they may desire is respect and human presence, an ability to be with them, to treat them as living rather than as the 'living dead', to companion them on a journey as far as we can, and then to let them go.

### A Sense of Belonging

A sense of belonging is important to human well-being. An important aspect of belonging is the opportunity for genuine human exchange. Exchange, by definition, means giving and receiving. In the face of multiple loss and uncertainty,



### Sontag

argues that blaming the ill for their illness, self blame among the ill, and isolation result from the stigmatization of disease.

people facing life-threatening illness may long for companionship that is genuine, mutual and affirming.

There are many ways for people to connect: in silence, in words, through touch and by sharing activities. As illness progresses, it diminishes the range of activities a person can undertake. Opportunities to go to movies, for walks or to play sports are examples, as are reading, listening and eating.

Other deeply rewarding aspects of relationships may not be lost. The need for privacy, intimacy and companionship for both ill persons and their loved ones should be accommodated in the building program and design.

### **Hope and Renewal**

Sociologist Arthur Frank writes about opportunities for renewal if not recovery in illness.<sup>14</sup>

We may easily forget that those facing life-threatening illness are still alive and have hopes and dreams too, although they may be changing. Throughout life-threatening illness people may hope for recovery. If their condition worsens, they may hope to be comfortable (pain and nausea free). One may hope not to become a burden. One may hope to remain at home or to return home. One may hope for more time, or for less time, or for reconciliation with estranged loved ones. One may hope for a miracle or for a peaceful and pain-free death.

I use this example to illustrate that ill people and their loved ones don't give up hope, although what we hope for may change dramatically from moment to moment in life-threatening illness.

Author Sherwin Nuland offers this perspective on hope for the dying:

"... the restoration of certainty that when the end is near, there will be at least this source of hope — that our last moments will be guided not by the bioengineers but by

### **A sense**

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those who know who we are. This hope, the assurance that there will be no unreasonable efforts, is an affirmation that the dignity to be sought in death is the appreciation of others of what one has been in life. It is a dignity that proceeds from a life well lived and from the acceptance of one's own death as a necessary process of nature that permits our species to continue ... It is also the recognition that the real event taking place at the end of life is our death, not the attempts to prevent it. ... In ages past, the hour of death was, insofar as circumstances permitted, seen as a time of spiritual sanctity, and of a last communion with those being left behind. The dying expected this to be so ... It was their consolation and the consolation of their loved ones for the parting and especially for the miseries that very likely preceded it."<sup>15</sup>

In a conversation with Arthur Frank, a sociologist who has twice faced life-threatening illness, he spoke of a "gestalt shift" from a well person being ill to being an ill person. He described that people close to life-threatening illness and death can take on a very Zen-like quality of living in the present moment. As the future is no longer taken for granted the present becomes increasingly valued.

With less focus on doing and on the future, the importance of being and a sense of the present as precious may emerge. People in a highly aware state of being in the present may be very sensitive to, and aware of, their surroundings. For this reason, Frank thinks a hospice should be visually interesting.<sup>16</sup>

In *Wounded Healers*, a book of poetry written by those touched by cancer, many of the selections speak to the experience of aliveness in life-threatening illness.

One excerpt reads:

"There is peril  
But it turns in surprising ways  
it brings you close up to the face of things  
right up near as can be  
where all life begs to enter."<sup>17</sup>



*There is peril  
But it turns in surprising ways  
it brings you close up to the  
face of things  
right up near as can be  
where all life begs to enter.*

## Storytelling

In the years I have been volunteering with ill and bereaved people, I have come to notice how often people relate their experiences and how powerful and moving their stories are.

In her book on the healing power of stories, doctor and therapist Naomi Rachel Remen notes:

"Real stories take time. We stopped telling stories when we started to lose that sort of time, pausing time, reflecting time, wondering time."<sup>18</sup> In stories, people tell about their human experience of illness: of facing the unknown, of facing loss, perhaps even of facing more intense emotion than ever before.

Ill people and their loved ones may be overwhelmed or devastated by the losses they face and may experience a "test of faith" or questioning of previously held understandings of how the world works. The time of facing death is often a time for reflection.<sup>19</sup> In listening to ill and bereaved people tell their stories, I have noticed how they often trace the account of the diagnosis and progression of illness, or of their lives, or of the death of their loved one. In this process of storytelling, they seem to bring themselves back to the present, perhaps with new insight about the state of their current understanding and their hopes and dreams.

Psychotherapist Jean Bolen writes about the value of 'witnessing':

"Any significant, soul-shaping event becomes more integrated into our consciousness, and more universal, when we can express the essence of the experience and have it received by another. I am convinced that any human being who can serve as witness for another at a soul level heals the separateness and isolation that we might otherwise feel. Witnessing is not a one-way experience; the witness is also affected by the encounter. To comprehend the truth of another person's experience, we must truly take it in and be affected."<sup>20</sup>

## Real stories

take time. We stopped telling stories when we started to lose that sort of time, pausing time, reflecting time, wondering time.

**Naomi Rachel Remen**

No matter how many stories exist, no two are the same, for the individual and their uniqueness shines through. Common themes may emerge, such as the ability to find grace and humor in difficult circumstances, or facing unbearable pain or despair or of the kindness of others — or all of these!

An interesting thing happens in the telling of stories. When two people are sharing stories about their lives, the barriers and roles are broken down. The listener becomes the receiver, the teller the giver. For the ill person, it is an opportunity to experience exchange, rather than feeling passive.

In the words of Dr. Dean Ornish:

“Telling stories can be healing. We all have within us access to a greater wisdom, and we may not even know that until we speak out loud. ... Listening to stories can also be healing. A deep trust of life often emerges when you listen to other people’s stories. You realize you are not alone; you’re travelling in wonderful company. Ordinary people living ordinary lives often are heroes.”<sup>21</sup>

In storytelling one may find connection, reflection and genuine companioning. Storytelling is personal, intimate. It creates a bond between teller and listener. In being very present as a listener, one is able to receive another’s experience.

In Bolen’s words:

“I am convinced of the importance of having a significant person bear witness to our lives. I often think that this is what I do as a psychiatrist: I witness my patients’ lives and thus know what it is like in their particular circumstances and what it means to be them. ... By listening with compassion, we validate each other’s lives, make suffering meaningful, and help the process of forgiving and healing to take place. And our acceptance may make it possible for a person who feels outside the human community to gain a sense of belonging once more.”<sup>22</sup>

Semiotician Umberto Eco calls storytelling “essential. The child asks, ‘what is a tree?’ If the mother points at one, she’s

## When

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not giving him any meaning. If she tells him the story of the seed and the soil and the water and growth and leaves and sunlight and wood, then it means something. We *make* meaning.<sup>23</sup>

### Summary

This chapter has raised some of the complexities and contradictions of the experience of life-threatening illness. For example, the poignant phrase “I’m not dead yet” reveals a desire for genuine connection, not to be abandoned to a liminal zone of the living dead.

The concerns raised in this chapter will inform the building site selection, program and design. Respect for individual autonomy is reflected in the project by the decision to make the residential component completely private.

The need to convey that those facing life-threatening illness are not being shunned by society informs the project in terms of location and program. To maximize opportunities for connection with others, this project advocates a series of small scale, community or neighbourhood based facilities with community outreach programs rather than larger regionalized services.<sup>24</sup>

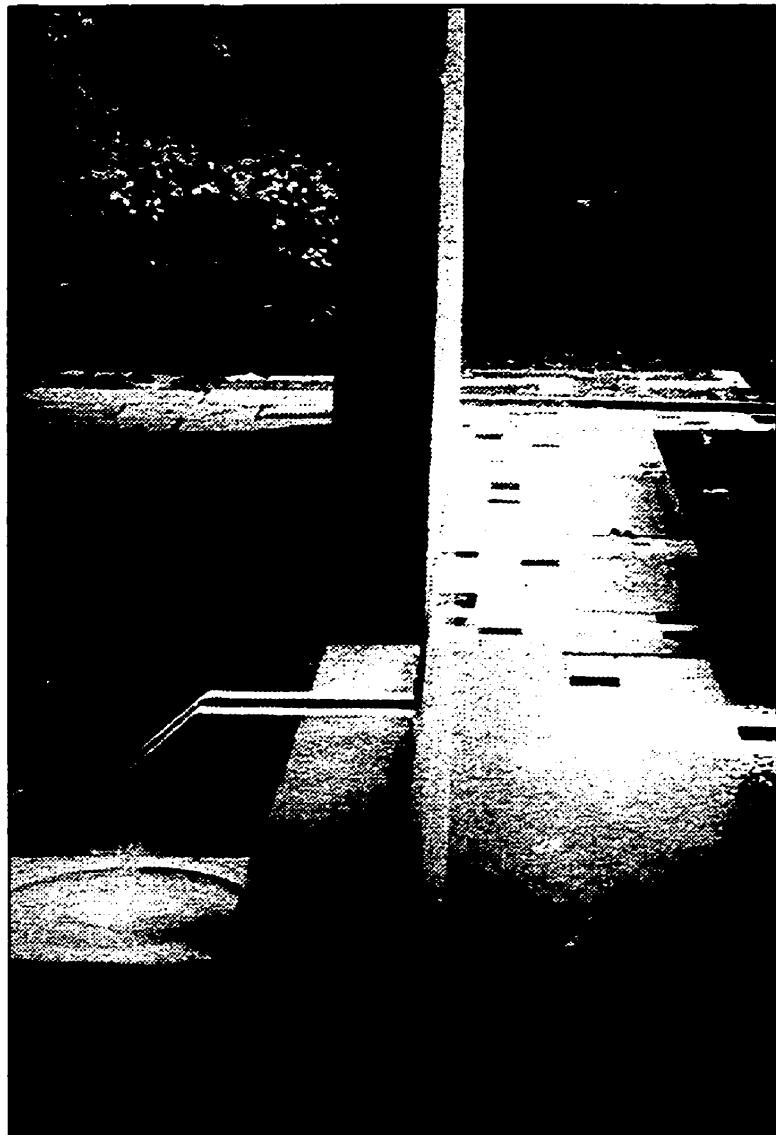
### By listening

with compassion, we validate each other’s lives, make suffering meaningful, and help the process of forgiving and healing to take place. And our acceptance may make it possible for a person who feels outside the human community to gain a sense of belonging once more.

Jean Bolen,  
psychotherapist

## ENDNOTES

1. Mullens, Anne. 1996, p. 28-45 offers an overview of changes and the development of 'rescue medicine'.
2. Neuland, 1994. p. 255 and Mullens, 1996. p. 36.
3. Mullens, Anne. 1996. p. 82.
4. This 1978 study is reported in Mullens, 1996. p. 84.
5. Mullens, Anne. 1996. p. 85.
6. Mullens, 1996. p. 87.
7. Mullens, 1996. p. 82. The author describes a study in which people responded positively to the opportunity for choice.
8. Frank, Arthur. 1991. p. 54.
9. In particular Arthur Frank, 1991, Susan Sontag, 1990 and Mullens 1996. Susan Sontag writes extensively about the language of stigma associated with certain diseases, AIDS and cancer among them in *Illness as Metaphor* and *AIDS and its Metaphors*, 1990. Others such as Foucault and Kubler Ross have brought these issues to the fore of popular culture and philosophy.
10. Sontag, Susan. 1990. p. 104.
11. Sontag, Susan. 1990. p. 58.
12. quoted in Sontag, Susan. 1990. p. 102.
13. Sontag, Susan. 1990. p. 6.
14. Frank, Arthur. 1991.
15. Neuland, Sherwin. 1994. p. 255-256.
16. From a conversation with Arthur Frank in September 1997.
17. Ross, Dorian in Remen, 1994. p. 89.
18. Remen, 1996. p. xxv.
19. The idea that this time of life is one of reflection was raised by Edna McHuchion, president of the Canadian Palliative Care Association, in a conversation in September 1997.
20. Bolen. 1994. p. 111-112.
21. Ornish as quoted in Remen, 1996, p. xvii. (italics mine)
22. Bolen. 1994. p. 110-111.
23. Watson, Patrick. (1998 October 17.) The Journalist as Story teller, *Globe and Mail*. p. D18.
24. This is the view of Tylene Katz, the dynamic force behind two free-standing hospices in Vancouver, gleaned from personal conversations and a presentation attended in the fall of 1997. Tylene argues convincingly that people need to remain in the context of their community for care and that the government must be involved (to care and work on ensuring quality of care) yet not dictatorial (if patient-centred care is to be placed ahead of bureaucratic ease.) Ms. Katz argues for a 50/50 funding split between government fundraising and private fundraising or services in lieu. (i.e. volunteer staffing to lower operating costs.)



are you there  
in the sound of snow drops melting  
from the tall trees  
on an early october evening?

are you there  
in the tears of loss  
rolling down my face,  
great rivers of grief  
carving deep pools in my heart?

are you there  
in the yellow stand of aspen,  
quivering in the mist  
on the hilltop  
at the edge of my dreams  
as I bless you this night?

Five free-standing hospices were visited for the precedent study. Free-standing hospices were chosen because this project is also the design of an independent hospice. This is due to the conviction that hospices should not be co-opted back into the system to which they are intended to provide an alternative, namely institutions such as hospitals.

In the words of Dame Cicely Saunders

"We need spaces for patients to look out on trees and for visitors to feel welcome. A good building can make a difference to the backs and feet of the staff and to the patient's spirits. It makes patients see that the creation to which they also belong is good — it can be trusted."<sup>1</sup>

The five hospices visited were 'purpose-built', meaning built for this function, rather than operating from renovated facilities. This chapter introduces the hospices selected for the precedent study. The sites visited were in:

- Worcester, Massachusetts
- Williston, Vermont
- Ithica, New York
- New Haven, Connecticut
- Concord, New Hampshire

At each facility, I met with personnel and toured the building. In some cases, photographs were taken and interviews were taped.

In the following section, each facility is presented. Ideas culled from staff as well as personal thoughts and responses are noted.

## We need

spaces for patients to look out on trees and for visitors to feel welcome. A good building can make a difference to the backs and feet of the staff and to the patient's spirits. It makes patients see that the creation to which they also belong is good — it can be trusted.

Dame Cicely Saunders

## The Connecticut Hospice New Haven

This inpatient facility opened in 1980. Its home care program began in 1974. It was the first purpose-built American hospice and was strongly influenced by St. Christopher's in London.

Originally housing 44 beds, it now accommodates 52 beds, 4 private and 48 in wards of four. It is located on a level site. The care area is on a single level, while the administrative and service functions are housed in a two-storey block.

### Architectural Ideas

Architect Lo-Yi Chan gives his views on the design intent: "We thought of the hospice building as a cloister ... a protected place. It is a community of people. And it is concerned both with body and spirit. Those are the feelings we want to engender."<sup>2</sup>

The New Haven hospice group wanted to create a therapeutic environment designed from the patient's point of view. They sought an at-home feeling and a place for families.

The building is designed as two V-shaped patient wings and a long service spine at the apex of the V's. Each of the V's embraces an exterior south-facing terrace. These patios are adjacent to the patient areas and are bed accessible. The service spine houses support spaces such as administration, pharmacy, laboratory and kitchen.

In order to minimize the anxiety and uneasiness for visitors and new patients, the building concept is to provide a series of anterooms or layers. Chan thought the anterooms would allow visitors to prepare themselves before seeing very ill people. He sees the anterooms as providing time to adjust and as an escape valve: "... we've created anterooms and layers that let you enter that space first and get in touch with your feelings and go on into the other space when you feel you're ready".<sup>3</sup>

## We thought

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Lo-Yi Chan,  
architect



**The Connecticut  
Hospice  
New Haven**



The long driveway is considered the first of the layers. With the goal of giving people time to adjust, the driveway enables those approaching to see the outdoor patios and people inside the building. The patient wings are approached through skylit family rooms with seating groups and fireplaces.

The majority of rooms are four-bed wards. These were selected over private or semi-private rooms in order to "create a sense of community."<sup>4</sup> The designer wanted to avoid the sense of isolation that is often characteristic of those facing life-threatening illness and to create a "sense of light, life and growing things".<sup>5</sup>

The wards are laid out on a double corridor plan — on one side there is a 'private' corridor housing bathrooms and services while the second corridor is conceived of as a 'social' corridor. It consists of greenhouse-style windows overlooking the outdoor patios. The ward room is separated from the social corridor only by a low partition wall.

The greenhouse wall and use of skylights were employed as a result of studies showing patients recover faster in natural light.<sup>6</sup> The architect also thought the skylights accentuate the passage of time. He perceived the movement of the sun, shadows, rain and snow as:

"...palpable. It gives a patient a point of reference to the outside world. The building won't be insulated from life. It's been established there are rhythms in day and night, and to deny that is wrong."<sup>7</sup>

### Observations

As noted, this hospice was inspired by St. Christopher's in London. Its founder, Cicely Saunders, views the hospice as a blend of hospital and residence.<sup>8</sup> The New Haven hospice reflected this perspective. The New Haven hospice seemed similar to a hospital due to the large scale of the project (52 beds), the ward-style bedrooms and the absence of a kitchen and dining area accessible to residents and visitors.

## The building

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Lo-Yi Chan

Yet the hospice feels less sterile than many hospitals, due to the greenhouse corridors and patios adjacent to the bedroom wards, and the natural lighting and views to outdoors from these areas. The nurses stations were integrated into the lounge areas as work stations on the periphery. This created a more casual ambience than the traditional counter-style nurses station.

According to planners and the architect for the New Haven project, the predominantly ward design at New Haven was created with the intent of promoting community. However, the ward layout does not provide adequately for privacy. The privacy provided by screens drawn around a bed in a four-bed ward is minimal.

The concept of layers of entry and spaces for psychological adaptation is interesting. Yet some of the adaptive spaces worked better conceptually than physically. The lounges adjacent the ward had little natural lighting. The entry lobby proportions were rather narrow and long, creating a sense that one was to move through it, rather than pause or rest or relax beside the fireplace.

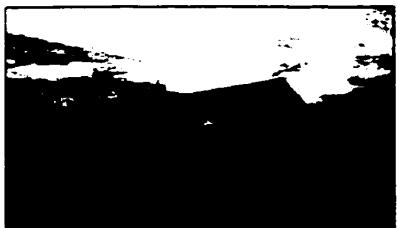
### **Vermont Respite House Williston, Vermont**

Vermont Respite House in Williston opened in March, 1991. It houses 14 private rooms, common areas and administrative and service functions.

### **Architectural Ideas**

Architect Timothy Duff noted that he had not visited any hospices prior to design. However, one of the key people in making Respite House a reality visited hospice programs in San Francisco, Hartford, Connecticut and Concord, New Hampshire, and found them:

“very medical — cold, sterile and uninviting. The goal was to make Vermont Respite House the opposite ... a warm home-like environment, keeping things on a smaller scale — user friendly.”



**Vermont  
Respite House  
Williston, Vermont**



The architect stated that the goals were to create a residential quality to the building, give individual climate control to the rooms, have easy access to the outdoors and to deliver the project on budget.

The building is laid out on one floor on a level site. It is a T-shape, with the entry and porch at the top of the T. Two corridors house patient rooms, while the third houses administrative functions and a chapel. The front entry leads directly to the living room.

### Observations

It appeared that the building functioned well in terms of accessibility to the outdoor areas and porches, having wide corridors and doors.

The low sloped front porch roof minimized the penetration of natural daylight into the living, dining and kitchen areas. As a result these rooms were rather dimly lit, unless augmented by electric lighting.

There was a cluttered feeling throughout the building, with the exception of the hallways and patient rooms. The dining area was so full of furniture it was hard to imagine being able to manoeuvre a bed or a wheelchair in the space. Such difficulty of access might contribute to social isolation. Staff noted that storage space was lacking, and this no doubt resulted in the impression of clutter in some areas. Special equipment and chairs filled the volunteer office, the tub room and any other possible spot.

Because the offices for the homecare nurses are in a separate facility, I wondered if the need for staff areas and storage was underestimated in the planning stage. The building was rather plain in spite of the 'special features' such as a fireplace and porches. This was due to minimal detailing and poor use of natural light in the common areas.

### The goal

was to make Vermont Respite House a warm home-like environment, keeping things on a smaller scale — user friendly.

## Hospice House Concord, New Hampshire

Hospice House is sited adjacent to a hospital, located there due to a land donation. As one approaches on the drive, a day care play area is adjacent to the front parking area, providing visual interest and animation.

The building houses ten private rooms, office areas, a porch, library, ample storage, laundry and two family rooms for visitors who wish to sleep at the house. It is on two levels, sited on a sloping lot and has elevator service.

### Architectural Ideas

The building features a central hub on the main floor flanked by two wings of five private rooms. The hub houses the entry, front porch, lobby, office, conference room, elevator, stairs, kitchen, dining and living areas and adjacent deck. Each wing has a shared shower and bath area. Stepping the plan slightly allows for windows on two walls in eight of the ten rooms.

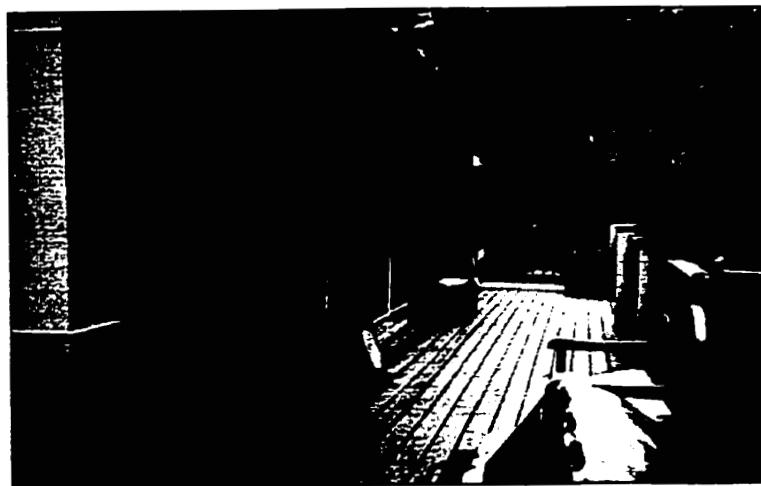
The lower level houses large storage areas, laundry and mechanical rooms, a quiet room and two guest rooms with ensuite bathrooms for loved ones to stay over or nap between visits. According to staff, these rooms are used by visitors who wish to be close at hand, yet feel the need for a rest or a break. Due to the slope of the site, the family rooms and quiet room have windows.

### Observations

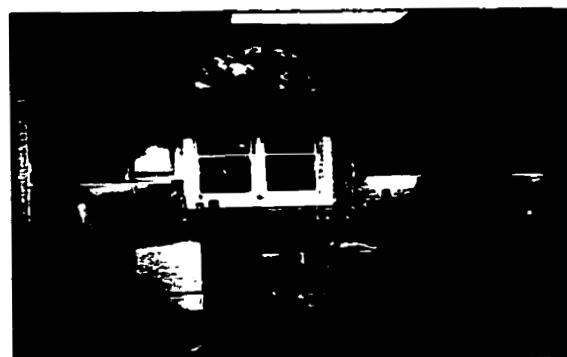
This building was well laid out on the main level. The lobby was large enough to allow people to pause for a time before entering the house proper. The office was well sited adjacent to the parking lot and lobby, so that staff could easily connect with people coming and going. A donor wall and table with information were also located in the lobby.

## A day care

play area is adjacent to the front parking area, providing visual interest and animation.



**Hospice House**  
Concord, New Hampshire



The location of the conference room near the front entry made it ideal to serve as a quiet room for family wishing to meet in private or make telephone calls. The flow from the entry to the dining and living room area was spacious. Visual interest was provided by cabinetry detailing at the dining room entry, changes in ceiling volume and a view of the deck and trees beyond.

Moveable cabinetry partitions could be used as a dividers within the large dining and living area, and staff noted they were used quite often to create different sized groupings.

Unfortunately, natural lighting in the living and dining areas did not penetrate the room, resulting in dim lighting, unless supplemented by electric lights. The lower level, while above grade, suffered from the same lack of natural light penetration in the rooms.

This building was well situated to take advantage of the adjacent play area to provide some interest for those using the front porch. The rear porch provided a more quiet, treed exposure.

### Hospice Center Ithica, New York

This facility opened in 1995. It houses 6 bedrooms, a chapel, a sitting area, kitchen, large dining and living area plus administrative offices for the entire home care and hospice staff. It is sited on two levels on a sloping site with a pond at the back of the property.

### Architectural Ideas

The main entry and a large living and dining area are located at the juncture where the six-bedroom residential wing meets a separate administrative wing. The interior wall at the juncture is gently curved. Structural roof trusses supporting the cathedral ceiling span the juncture area and parts of the administrative wing and the curved wall are penetrated by

openings. These features create an interesting visual link between the functionally discreet areas.

The street side of the residential wing houses one bedroom, a chapel, nurses area, bathing facilities and a small sitting and dining area. The remaining five bedrooms face the rear yard and pond. A deck along the back and side of the residential wing provides outdoor access from each room.

Built on a sloping site, the lower level has ample storage, a second kitchen and a large multi-purpose room for staff meetings or special workshops. Separate from the main building on the lower level is a private suite. It was built as a live-in manager's suite but proved to be too isolated from the residential wing for this to work. It is currently used as a rental property.

### Observations

The building has ample natural lighting, provided by large windows as well as skylights and dormers. The play of natural light on exposed wood truss supports in the main living/dining area is dramatic. This large space lacked definition. When two or three people sat at one end for a conversation, the space seemed too big for intimacy. This area needed a focus, such as a fireplace or groupings of furniture, to avoid that 'lost in space' feeling.

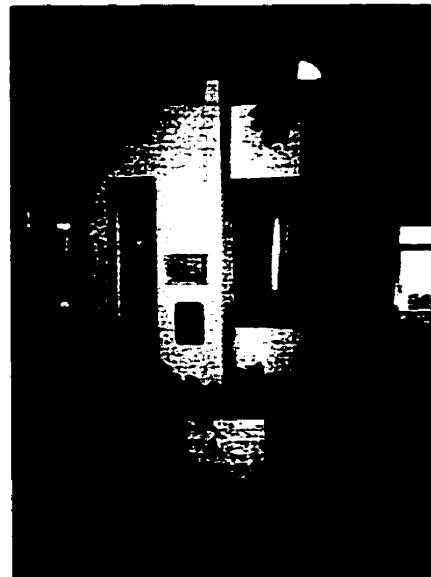
A small-scale sitting and dining area within the residential unit is provided. The nurses area was a sky-lit space within a wide corridor. It had the quality of a casual office or library nook, created by a grouping of furniture, rather than a room behind a counter. It was within sight of the residential common area, making staff easily accessible.

Staff reported that it was difficult to move beds onto the deck adjacent to the bedrooms, as there was a one-inch ledge at the threshold.



## Hospicare Centre

Ithica, New York



The grounds were fairly undeveloped, although there is a landscape garden plan in place that identifies four garden areas to be created: a south terrace spiral garden adjacent to the front entry, a chapel garden also facing south at the front of the building and two rear gardens, one for retreat and a shaded strolling walk.

**Hospice Residence of the  
Visiting Nurses Association  
Worcester, Massachusetts**

This facility was the newest of the five purpose-built hospices I visited. In fact, it was still under construction when I was given a tour by the project architect David Kron of Lamoureux, Pagano and Associates.

The building has ten private rooms and is located on a sloping site at the end of a residential cul de sac. It is designed on two levels to be compact enough to take advantage of the heavily treed lakeside site, while leaving space for a garden and patios to be developed on the lake side.

**Architectural Ideas**

In this building, the front or entry side is actually the back. The street side at the upper level is at grade with the parking lot, which is primarily hard landscaping. Services are housed on this side and the facade is penetrated by few window openings. At the lower level this side of the building is below grade, and service areas are housed adjacent to the underground wall.

The building opens to the rear to face the lake and woods. The 'rear' then becomes the front. It is the focus of each of the 'people' rooms. The building is stepped in order to achieve residential massing and take advantage of the views from the site. Each of the ten bedrooms has a private balcony (upper level) or access to the garden at grade (lower level).

On each level there are five bedrooms. The entry hub houses an entry vestibule, fireplace, living, dining and kitchen area with a semicircular porch overlooking the lake and stairway to the lower level.

On one side of the hub there are three bedrooms facing the lake, with an office and storage on the street side. On the other side of the hub there are two bedrooms on the lake side and a coat room, elevator, tub room and janitor's room on the street side.

The bedrooms on the lower level are beneath those on the upper level. The hub at the lower level houses a second living room, a small kitchen and a multi-purpose / meditation area that can be separated by folding wood doors.

### Observations

The woodsy location, small scale, fireplaces and natural finishes created the ambience of a private guest house or retreat centre. When I shared this observation with the architect, he told me that in order to secure the mortgage funding, the bank requested that the building be designed to function as a small private hotel or guest house.

As at the other facilities I visited, the nursing area is deemphasized. In fact, here it is eliminated, although there is a locked room for medication storage and preparation.

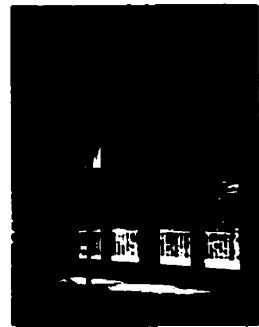
The bedrooms are spread over two levels and both ends of the building. I wondered if the layout would create a feeling of isolation in the two end basement bedrooms. While this might be a plus in a small private hotel or guest lodge, I don't think it will be in a hospice. It may be on the edge between privacy and isolation. In addition, one of the bedrooms on the lower level looks out at a concrete retaining wall extending 22 feet beyond the edge of the building — an unattractive thing to look at.

The other hospices on two levels organized patient bedrooms on the same level. In this case, one wing of five bedrooms per floor would have made it easier for staff to be in



**Hospice Residence of the Visiting  
Nurses Association**

Worcester, Massachusetts



close proximity to the people they are caring for. There are no separate rooms for family or guests to stay over, but the bedrooms are large enough to accommodate sofa-beds. There is no reception area in the building, and the office does not open onto the entry lobby, as it did at the hospice in Concord. This could easily have been done, as the office is adjacent to the main entry. The office windows overlook the parking lot, allowing office staff to see people approaching.

### **Programming**

Two of the five hospices visited housed administrative offices for the staff of the entire hospice program as well as for those working at the hospice unit.

All five of the facilities operate bereavement programs from the hospice building rather than off-site.

Four of the five hospices had non-institutional kitchens, available to building users. All five facilities visited de-emphasized or eliminated the conventional nurses station.

One of the hospices visited had a guest suite for visitors. Three hospices had hide-a-bed couches in the bedrooms. The New Haven hospice could accommodate guests in a separate room, although it lacked bathroom facilities. One of the hospices had a separate apartment, originally designed for staff, and later used for revenue.

In addition to these hospices, I toured several others. They are: Hospice Calgary, Canuck Place — a children's hospice in Vancouver, and two hospices in the Boston area located in renovated houses.

Hospice Calgary has facilities for a day-program for ill people and for children's programs, although these are not in the same building as the hospice unit.

At Victoria Hospice, a number of programs are offered outside the unit. These include a children's program, kids' summer camp, staff and volunteer retreats and bereavement drop-in programs. This is due to inadequate on-site space, rather than by design.

## Siting

The setting of the five hospices visited is somewhat pastoral. The siting seems to reflect a desire for a protective, quiet location. Upon reflection of the issues of the stigmatization of the ill and resultant isolation raised in Chapter Two, it seems important to question whether isolated settings are appropriate. If the hospice is serving an urban community a remote setting may contribute to the sense that the ill should be 'removed' or sheltered from the mainstream of life.

## SUMMARY

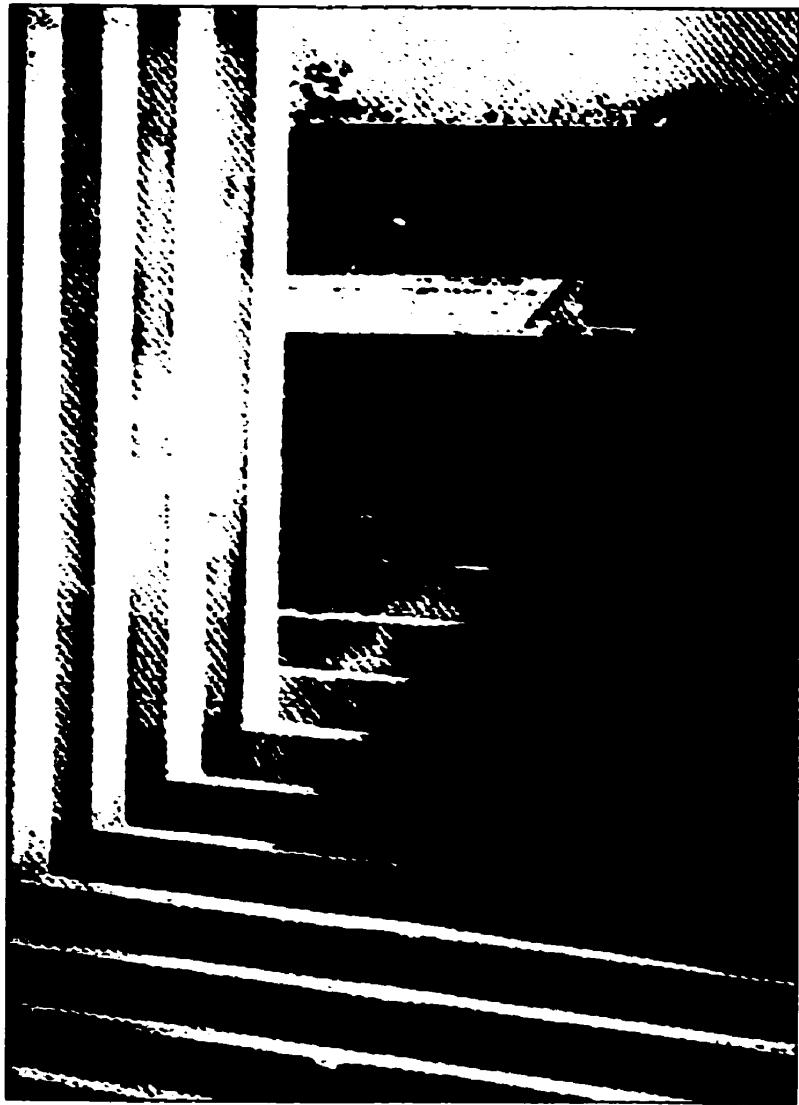
It is interesting to consider the five hospices visited for the precedent study from the perspective of the question "What is a hospice?"

- The view of hospice as a blend of hospital and residence, as espoused by Cicely Saunders and evident in the New Haven hospice.
- Architect Lo-Yi Chan introduces the concept of cloister, and a layering of spaces.
- Residential models, aiming to normalize death by making hospices look like homes. The risk here is that not enough depth of thought has been applied to the consideration of what is being sought in this process. I believe the residential model is appropriate in some ways, such as for normalizing the range of activities and autonomy available to people, while it is unsuitable in other ways. This point is explored in Chapter Four.
- The model of hospice as a guest house or retreat.

### Endnotes

1. Kron, Joan. (1976, March 1.) Designing A Better Place to Die. New York. p. 49.
2. Author unknown. (no date available, article provided during research interview) Designed for Dying: Building for Living. Bridgeport Post and Associated Press. p. F1.
3. Designed for Dying. Ibid.
4. Designed for Dying. Ibid.
5. Designed for Dying. Ibid.
6. Kron, Joan. (1976, March 1.) Designing A Better Place to Die. New York. p. 48.
7. Ibid.
8. Stoddard, Sandol, 1992. p. 88.
9. These comments were provided by Susan Abell of Vermont Respite House. She forwarded this information in November 1997, in response to some questions I had sent via email. She had consulted with Gary Elsey, former President of the Board of Directors, who was involved with the project from the very beginning, for the answers to my questions.

oh desire  
toes long for cool grass  
ribs long for earth  
eyes long for luminous clouds  
skin longs for breezes  
singing caresses  
with each sweet breath



In this chapter, the nature of the proposed hospice building will be considered. Research and stories from previous chapters are reviewed and new material is introduced.

### Conceptual models: What is this hospice place?

In Chapter 3 several concepts of hospice were explored. They ranged from a view of the hospice building as a cross between hospital and residence, (New Haven), to the view of hospice as a residence (Vermont Respite House) to the hospice as a guest house or retreat, (Worcester).

The following section considers other models that might be useful from a conceptual viewpoint, namely: residential, hotel and cohousing. The residential model is reconsidered in terms of its potential for affirming life. The models of a small private hotel and of a unique residential innovation called cohousing will also be considered.

The residential concept for hospice has both value and limitations. Some of the beneficial characteristics are autonomy, variety of activities, comfort and exposure to nature. These will be reviewed in more detail later in the chapter, as activities of life and living are presented.

However one might choose to use the concept of 'home' to iterate positive characteristics, it is important not to extend this metaphor to social ties.

Commonly one's home is shared with friends or relatives. Yet people at a hospice may have little in common other than life-threatening illness. They often have a family of origin or a family of friends forming their social support network.

### However

one might choose to use the concept of 'home' to iterate positive characteristics, it is important not to extend this metaphor to social ties.

While these systems and networks will be stressed during life-threatening illness, the individuals involved have established ways of coping. It is important that hospice support existing networks, rather than replace them.

Victoria Hospice counsellor Elizabeth Causton compares the social support network to a group of dancers. The change to the dance during life-threatening illness may be the equivalent of the choreographer (or a minor dancer), sitting down on the dance floor. All of the other dancers are faced with adjusting.

Causton sees the hospice role as one of staying off the dance floor and offering observations and support to empower the dancers rather than attempt to teach everyone new choreography.<sup>1</sup>

In recognition of the existing social support network of the ill person, it is helpful to look beyond the concept of 'home' for a model that offers autonomy and community, rather than family.

The 'hotel' type is considered for the autonomy and hospitality it provides. The concept of cohousing is examined for its feature of blending autonomy and community.

Imagine the difference between visiting family or friends and staying in their home compared with staying in a guest house or hotel. In a hotel or guest house, the stay is temporary. One rents the space. A degree of autonomy is understood to exist in this arrangement. Services are available to guests, yet guests do not feel that requesting services is burdensome, as one might while staying in someone's home.

There are benefits to considering a hospice in this way: the 'guest' or ill person and their family have a degree of privacy and autonomy afforded by a private room and bathroom. Like a hotel, many services may be provided, including room service or dining room service, laundry and housekeeping. In this model, medical care would be seen as one of the services provided.

While the hotel concept provides a degree of autonomy, it offers limited opportunity for connection or community. It

In recognition of the existing social support network of the ill person, it is helpful to look beyond the concept of 'home' for a model that offers autonomy and community, rather than family.



Cohousing  
Models



offers such a high degree of privacy and autonomy that it could engender isolation, something noted in Chapter 2 as a very difficult aspect of life-threatening illness.

The concept of cohousing is of interest for the blend of privacy and community it offers. It is a model of resident-developed communities initiated in Scandinavia that has gained popularity in Europe and North America in recent decades.<sup>2</sup>

Units or homes are usually resident-owned and cluster around a common house with shared facilities. Each household is self-sufficient and its occupants choose how much they want to participate in community activities. Although the idea of private ownership is not relevant to a hospice, control is. (see Chapter 2).

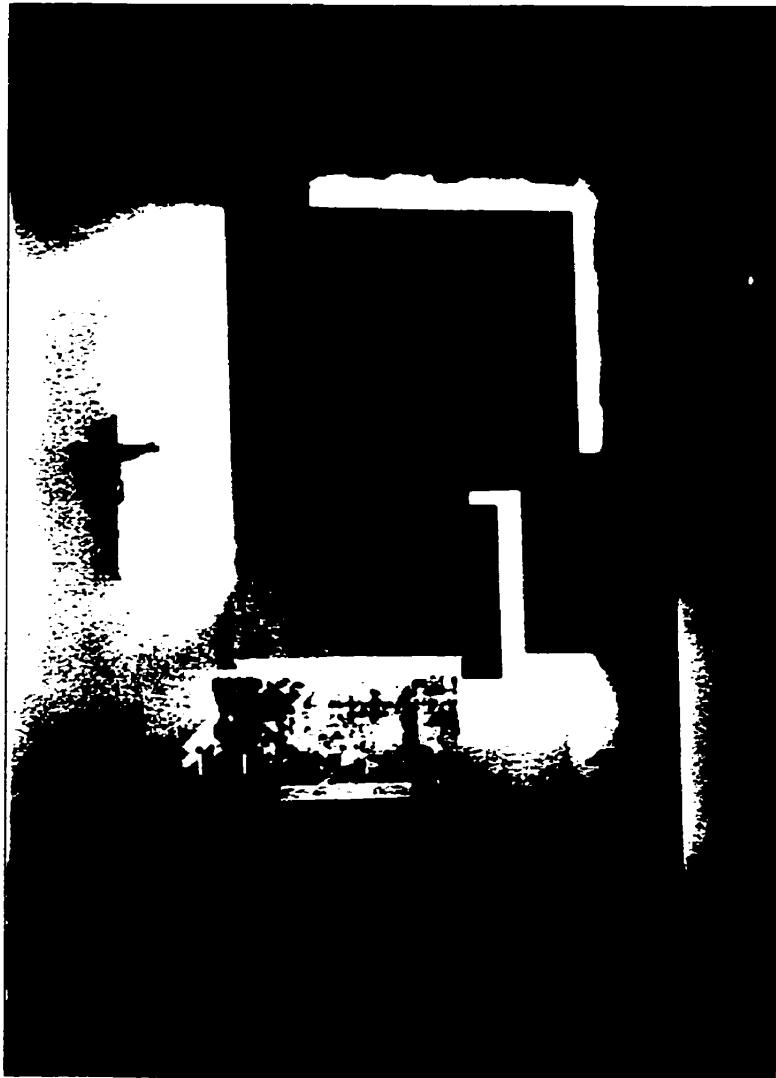
The interplay of privacy/autonomy with community facilities and communal activities is a useful model. In cohousing the use of communal facilities and participation in community activities is completely at the discretion of the user. This complements the hospice philosophy of respect for the individual.

The models of hotel, guest house and cohousing are secular. One might also consider a monastic model, as the experience of life-threatening illness may be a time for deep reflection. All of the hospices studied had programmed space specifically for quiet reflection or meditation. The inclusion of such space reveals an awareness that individuals confronting loss need time for thinking, for prayer and reflection and/or to simply be quiet.

It is a paradox that in facing life-threatening illness, emphasis on close ties with family and friends and on living until one dies implies connection and interaction, while at the same time there is often a deep need for quiet and being rather than doing.

A further aspect of the paradox is that ill people and their

**It is a paradox that in facing life-threatening illness, emphasis on connecting with family and friends and on living until one dies does not imply a cloistered existence, while at the same time there is often a deep need for quiet and being rather than doing.**



Sacred Space  
Chapel of St. Ignatius



Ronchamps

loved ones may feel overwhelmed by changes in physical condition, by the sometimes complex regime of symptom management options, by the numbers of people involved in the multi-disciplinary team approach and by the sense that there are things to be completed or taken care of in preparation for death. The experience may be like that of a roller-coaster, with external information and internal responses changing from moment to moment.<sup>3</sup>

The previous discussion of conceptual models for hospice highlights issues of hospitality, privacy, autonomy, community, comfort and protection. These inform the program and selection of the site, as does hospice philosophy.

### **Further Considerations for Site and Program**

Usually people coming to a hospice in-patient unit are admitted for assessment because of an unwelcome change in their condition such as increased pain, or because caregiving at home is no longer a viable option. At a time when people are facing this unwanted change (illness), the importance of having choice is particularly significant.

The residential model for hospice suggests a degree of control over environment and activities. In our homes, our preferences are expressed. These preferences are multiple, ranging from control over room temperature to choosing what activities we will do and when, to our choice of food, music and decor.

Access to the outdoors, both visually and physically, is usually easy from one's home. At home, we have a relatively high degree of control, albeit over a small sphere. We get to be "a big fish in a small pond".

### **Program**

One of the ways the program can increase the control or choice of the users is by providing opportunities for the types of activities and ways of relating that people feel most comfortable with.

Thought has been given to the range of activities people are accustomed to. Some of the obvious activities of daily life and of home are eating, sleeping and bathing as well as recreational activities such as reading, listening to music or watching TV and spending time outdoors. The building should allow for as many typical activities as possible.

Unlike most hospices associated with hospitals, four of the five hospices visited for the precedent study had full kitchen and dining facilities. Such facilities are an important aspect of the program. Food and 'the breaking of bread' together have a long history of communion, as does storytelling.

Food is so much more than physical nourishment — it is ritual, it is sharing. It may be used punitively "eat this — you have to eat this it's good for you" or with great empathy and caring, such as in preparing a special broth or food for someone with a poor appetite.

If full kitchen facilities are available, both ill people and their loved ones can choose not only what to eat or cook, but when and with whom. One can imagine the smell of freshly baked bread wafting through the building. A sense of belonging may be engendered by family, staff, volunteers and residents sitting together for a bowl of soup at lunch time.

Even a person too ill to eat may wish to be present to share a special meal with loved ones — an opportunity that is missed if they are not up to travelling and no kitchen and dining facilities are available on site, or if the dining area is inaccessible.

Kitchen and dining facilities also provide an opportunity for staff and family and volunteers to share time together in a casual and reciprocal way, perhaps momentarily shedding their roles. Having these facilities may also increase the likelihood that devoted loved ones will remember to eat. It is not uncommon for family and friends to neglect them-

## One of the

ways the program can increase the control or choice of the users is by providing opportunities for the types of activities and ways of relating that people feel most comfortable with.

selves in their desire to companion an ill friend or family member.

The building program for a hospice that aims to affirm life should allow opportunities for a diversity of individual approaches for ill people and their loved ones. One person's view of relaxing may be having a beer while watching soap operas, another person's may be meditation.<sup>4</sup>

Over the years I have often asked people what they do to nurture themselves. Common replies are: spending time in nature, spending time with loved ones, and spending quiet time alone. Following these are self-expressive and creative activities such as gardening, cooking, playing music, singing, dancing, writing and painting.

The building program and design should include opportunities for intimacy and allow space for quiet reflection. Visitors should be accommodated and patient rooms should include space for loved ones to stay over.

Opportunities to meet with people informally to gain support and share stories are important. To facilitate this, the design should afford opportunities for informal interactions.

Ease of access to the building and outdoor areas requires that live-in rooms are best located on grade or have balconies accessible to hospital beds.

The entire building should be wheelchair accessible, if not bed accessible, with the exception of service areas.

Attention should be given to the play of light, views and access to the outdoors from the hospice. The qualities of natural light invoke a sense of the ever-changing rhythms of nature. The natural world is constantly changing and renewing itself. It is a beautiful metaphor for change as well as providing real time, real place interest.

## The building

program and design  
should include  
opportunities for  
intimacy.

## Nature is

constantly changing and renewing itself. It is a beautiful metaphor for change as well as providing real time, real place interest.



## Endnotes

1. This metaphor was presented by Elizabeth Causton during a series of training sessions for emotional support volunteers in the spring of 1997.
2. See McCamant and Durrett, 1988. *Cohousing: A Contemporary Approach to Housing Ourselves*.
3. During a volunteer shift at Victoria Hospice in January 1998, one ill woman referred to this constant sea of faces as 'a parade'.
4. This was the response of one terminally ill man's wife when asked what she did to cope with the stress she was encountering. The point here is that coping styles are very individual.



what is beyond sorrow  
is it a place where pain  
becomes friend, embraced  
rather than the secret  
stalker who haunts me  
the terror and despair

is it a place  
where WHY stops shouting  
and, working in the garden  
and, watching the seasons  
and the small bugs  
I see...  
mystery  
life begets death  
endlessly

is it a place where  
I become you and you become me  
touching eternity ?

The project proposes a community hospice. It is seen as one of a series of small, individual facilities offering services related to life-threatening illness and bereavement, open to everyone in the neighbouring community.

Location is one of the most overt means of conveying the message that those using the facility are not being cast into a zone removed from society. As a community hospice, the facility must balance community involvement with privacy.

### Site

The site is in Victoria, B.C. It borders the 154 acre *Beacon Hill Park* to the south, *St. Ann's Academy*, a 6 acre heritage property to the north, two residential neighbourhoods, *Fairfield* and *James Bay*, and the significant downtown precinct containing Victoria's scenic Inner Harbour, Provincial Legislative Buildings and Provincial Museum.

This community hospice would serve the neighbourhoods of James Bay and Fairfield. The area houses an eclectic mixture of low and high-rise densities, historic and modern architecture and a multitude of uses: residential, commercial, institutional, office and recreational, including the Inner Harbour and parkland.

In considering a site two major factors came into play: accessibility of the site to extended family and friends and the context of the site in relation to nature. A site was located that has good access to city transit and open public green space. This affords a degree of convenience for family and friends to access the site. Virtually every hospice visited and every person interviewed mentioned exposure to nature by



Neighbourhood adjacent to site



Aerial view of site environs  
Victoria, B.C.

way of views or access to a garden as important for the healing, interesting and affirming qualities of nature.

This site was chosen for its park-like setting and strong tie to vibrant urban life. This seems a fitting expression of the paradox of living until death and at the same time the gestalt shift Arthur Frank speaks of, in which one focuses more on being and less on doing.

The proposed site formerly housed St. Ann's High School Annex and the Victoria Conservatory of Music. There are no definite plans for re-use of the site, although BCBC (British Columbia Buildings Corporation) predicts the existing building will be demolished and returned to parkland.

### Terrain Vague

In his essay in *Present and Futures, Architecture in Cities* Ignasi de Sola-Morales notes “The cultural experience of the city is made up of human fabric in which the survival through time of the signification of places should not be underestimated.”

de Sola-Morales describes *terrain vague* sites as responsible for much of the city’s voids and porosity. Typically, the term *terrain vague* refers to areas abandoned by industry, railways, ports or as a result of the withdrawal of commercial or residential activity. Also included are residual spaces such as along the banks of rivers and areas cut-off by highways.

Although it does not fit this typical description, in significant ways the selected site fits the French description of *terrain vague*. In the words of de Sola-Morales:

“...both the notion of *terrain* and that of *vague* contain an ambiguity and multiplicity of meanings that make this an especially useful term to designate the urban and architectonic category with which to approach the places, territories or buildings that share a certain double condition. On the one hand, *vague* has the sense of vacant, void, devoid of

### The site

was chosen for its park-like setting and strong tie to vibrant urban life.



Site map  
January 1863

activity, unproductive, in many cases obsolete; on the other hand *vague* has the sense of imprecise, undefined, vague, without fixed limits, with no clear future in sight ... These areas of *terrain vague* are ... the privileged sites of identity, of encounter between present and past."<sup>2</sup>

The selected site is characterized by the double conditions Sola-Morales is referring to. It is located in a vibrant and eclectic area of the city, yet it is within a quiet precinct that appears to have been forgotten or frozen in time as the city developed.

In his essay on *terrain vague*, de Sola-Morales argues that it is the sense of vacancy and absence of such sites that needs to be preserved. "Only by according equal attention to the values of memory and absence and the values of innovation will we be able to maintain confidence in a complex and plural urban life."<sup>3</sup>.

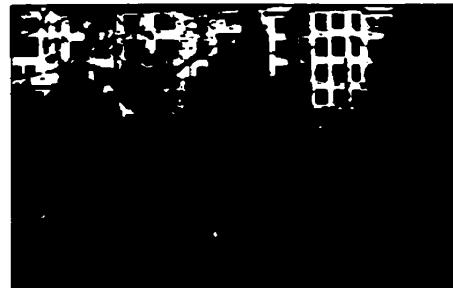
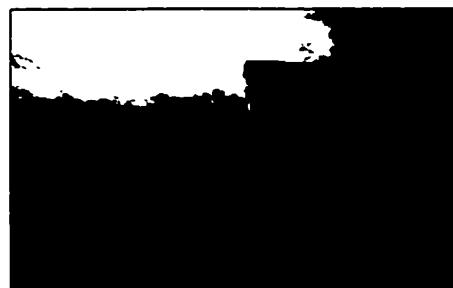
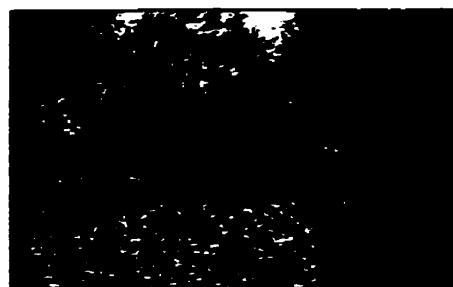
In many ways the physical description of *terrain vague* could be used as a metaphor for the psychic terrain death and bereavement occupy in our consumptive and productivity oriented post-modern culture. It is an area we signify by our vagueness and ambiguity toward death. This has been discussed in earlier chapters examining the context of palliative versus curative approaches to life-threatening illness.

In the words of de Sola-Morales "... our post-industrial culture calls for spaces of freedom, of indefiniteness and unproductivity."<sup>4</sup> I agree with Morales that in our increasingly financially driven post-modern culture, we need spaces of 'freedom, indefiniteness and unproductivity'.<sup>5</sup> I am not referring to unproductivity as sloth, but define it for these purposes as referring to a different realm than the consumptive. I refer to the realm of poetics, of the soul, and to exploration and freedom of expression untied to conditions of sponsorship.

The hospice view of dying and bereavement offers a challenge to our consumptive, commodifying cultural motivation



View of site bordering park



Views of St. Ann's Academy grounds

by proposing that death and bereavement may be rich, evocative and fundamental aspects of life's journey, *openings*, not merely glitches in the path of progress and productivity.

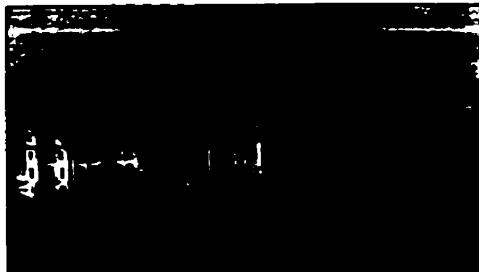
Another characteristic of *terrain vague* sites is they exist as "a consequence of history".<sup>5</sup> In a city largely defined by its connection to nature (the sea and coastline), Beacon Hill Park further claims green space within the urban context. Established in trust for parkland in 1882, this 154 acre park borders the south edge of the project site. St. Ann's precinct, immediately north of the project site, has remained virtually undeveloped since 1910. The grounds are complete with an apple orchard - a notably distinct and delightful anomaly in the larger urban context.

### History of St. Ann's Precinct

The six-acre site known as St. Ann's was owned by the Catholic Church from 1858 until the 1990s. The site housed a school and convent. The first wing of St. Ann's was constructed in 1871. In 1886 an east wing was added, tripling the size of the Academy. Also in 1886 the Chapel (built in 1858) was relocated to the Academy site. In 1910, a west wing was added, named the Hooper wing after its designer and builder.

By the 1920's, an annex was built to the south of St. Ann's to accommodate additional school space. It was added onto in the 1950's and again at a later date. The Academy and annex were vacated by the Sisters of St. Ann in 1973. The Academy was used for various purposes from 1973 until 1993, when restoration began under the terms of an agreement known as the Victoria Accord.

The Academy was converted to public use as offices for the British Columbia Ministry of Education in 1997. The restored chapel and auditorium and grounds are open to the public, and available for rent for individual and group functions, such as weddings, concerts, lectures and meetings.



Early postcard of St. Ann's Academy

## Design Concepts

The neo-modernist language of the building developed from a phenomenological approach to design. Clarity of form (for user orientation) and space (for bed accessibility) and layering of space (for privacy) were achieved through a division of 'servant/service' areas from 'served' space and the design of the structural system.

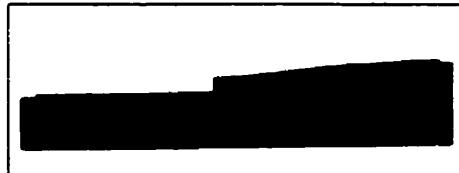
The structural design employs the solidity of the concrete spine retaining wall as an anchor. The wood post and beam structure is designed as a series of ribs projecting tangentially from the concrete spine. This allows the walls parallel to the length of the spine to be structurally free, or non load-bearing. This achieves the freedom expressed in the conceptual model, namely of providing for transparency, translucency or solidity along the length of the east-west walls parallel to the spine.

The concern with experiential qualities of light and sound, along with connection to nature were generating forces in the design. The building design is closely tied to the topography of the site and to the program.

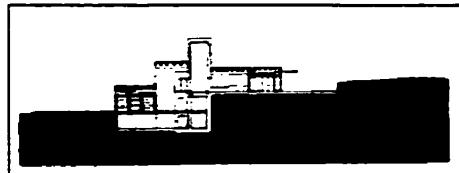
## Program/Layering

The building is conceived of as a series of layers. The lower level is the public layer. It faces directly onto the street (Academy Close) and nestles against the retaining wall of the sloping site at this level. The service level is primarily below grade.

The lower level of the facility, on grade with Academy Close, is fully dedicated to community use. It houses a cafe, reception, poetry and fiction reading room, staff and volunteer offices, areas for day programs and bereavement services which include expressive therapies such as music, dance, art and exercise classes as well as support groups and physical therapies such as massage, reiki and acupuncture.



North-south site section



North-south section

Having community-oriented programming at street level gives the hospice the opportunity to fulfill one of its mandates: exposure and accessibility to the community. This may contribute to reducing the stigma associated with death and with hospice as a place for dying rather than for living until death.

A community-oriented public face to the building face has potential benefits and spin-offs, such as:

- increased community involvement and support
- potential for better understanding of hospice
- better awareness of hospice services
- increased public profile
- opportunities for public education

The role of the cafe is multi-faceted:

- to create animation and vitality
- to diffuse rigid cultural barriers that isolate life-threatening illness from “everyday life”
- to offer a facility and neighbourhood amenity to contribute financially to the project.

The upper level is a private layer. It faces directly onto Beacon Hill park at grade. The sloping site allows rooms at the park elevation along the south side to open directly to the outdoors. This level of the building houses the residential component of the hospice: bedrooms, kitchen, dining and bathing facilities for those living at the hospice or staying for respite care.

The patient rooms are conceived of as a further layer of private spaces within the private residential level. This is to provide a cloistered sense for the most private areas, the residential bedrooms.

## Boundaries

The project works with the following descriptions of boundaries:

Diffuse: visually and physically penetrable

Clear: visually penetrable, physically impenetrable or visually impenetrable, physically penetrable

Rigid: physically impenetrable

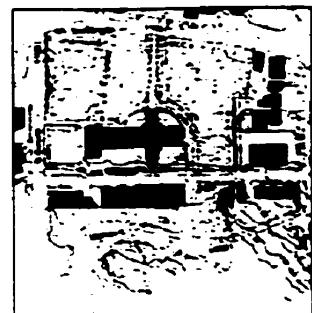
Within the building, these boundaries work with layering to provide opportunities for privacy, interaction and control.

## Site: Disjuncture and Connection

As previously outlined, the site currently houses a building identified as 'the St. Ann's annex', re-used as a conservatory of music and now abandoned. As it exists, the building, site and fencing act as a barrier or rigid boundary between the St. Ann's precinct and Beacon Hill Park.

On the south side of St. Ann's precinct, adjacent to the project site, there are 3 boundaries: One is a row of tall trees. These I refer to as a clear boundary, being visually boundaries yet physically penetrable; the second boundary is a chain link fence which is a rigid boundary meaning it does not allow physical access. Fortunately, the fence does not extend the full border of the site, allowing access between the orchard, grounds and street at the eastern end of the site. The third boundary is also rigid. It is a retaining wall on the St. Ann's site.

On both the project site and the St. Ann's site to the north, the retaining walls act as significant boundaries that disconnect the historic precinct from the park and from the street. One of the aims of the project is to mend, bridge or re-connect these disjunctions.



Site, existing



Paper sketches exploring connections to park

The project provides an urban courtyard entry to the facility from Academy Close at the western (down-town) edge of the site. This provides a sanctuary at the urban level and a connection between the street and the park.

At the eastern edge of the site a public pathway links the park and St. Ann's grounds (where the St. Ann's edge is a diffuse boundary, allowing physical access to the site). These connections transform the experience of the site from rigidly bounded and inaccessible to that of an accessible sanctuary for those in the downtown core to find a quiet space for reflection or simply to enjoy the unique setting.

### **Grid and Boundary**

Another aspect of the site, most obvious in plan, is its distinct edge conditions. At Academy Close, the north edge of the site is 'on grid', aligned with the linear city grid pattern. To the south, the site is currently bound by a retaining wall, also 'on grid'. The land and road to the south of the site (now incorporated into the site) and the park are distinctly 'off grid'.

In addition to identifying the terms 'on grid' and 'off grid' to identify physical characteristics, a theoretical/experiential framework was developed regarding 'on the grid' and 'off the grid'. These are characterized on the following page.

**ON THE GRID**

ego based / self based / self as centre

activity oriented - doing

multi-tasking/diffuse

future oriented / planning, scheming

thinking realm / mental

taking things for granted, familiar

personal control

**WHO WHAT WHERE WHEN** questions

busy mind

**OFF THE GRID**

contextual / holistic / cycles / big picture

being / quiet / reflective

mindfulness/attentive/focused

real time / present orientation  
( moment by moment...)

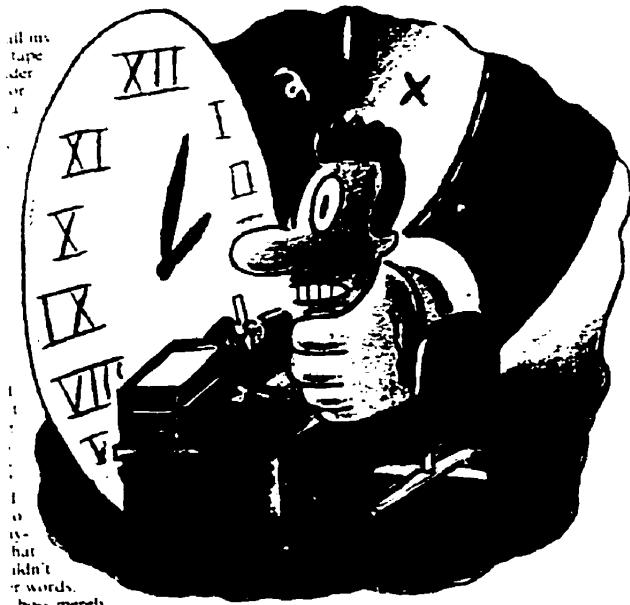
experiential realm / feeling

uncertainty / opportunity / serendipity

big picture focus - reflective, philosophical

**WHY** questions

contemplative mind



As I worked with conceptual design and design development, I began to see these less and less as separate realms (a dichotomy) and more and more as a continuum. We are all capable of moving along this continuum during our lives, perhaps even within a given day or hour.

Being polarized at one end or another of this framework can be very isolating. There is value to be found in a holistic view in which experience is seen as connected to, or part of, a continuum of life and experience.

The 'gestalt shift' Arthur Frank talks about (see Chapter 2) is an experiential movement toward the 'off grid' realm of experience, from the 'on grid' realm that is predominant in our culture.

The treatment of an ill person from an 'on grid' perspective - namely from a bio-mechanical, thinking (analytical, diagnostic) model may be useful, but it is not sufficient.

The recognition that a person experiencing an illness is experiencing in the realms of physical sensation, emotions and mental and spiritual perceptions is the *raison d'être* that led to the creation of the hospice movement. The hospice movement reflects a paradigm shift from a dualistic approach to a holistic view incorporating both 'on grid' and 'off grid' experiences — a place of belonging, of affirming life in its diversity and richness along the continuum of experience.

The design seeks to honour the need for a sense of belonging, the need for reflection and the need for reconciliation. These needs parallel Henry Nouwen's conception of 'the three movements of a spiritual life':<sup>6</sup>

the movement from loneliness to solitude  
one's relationship to oneself

the movement from hostility to isolation  
one's relationship to others

the movement from illusion to prayer  
one's relationship to the bigger picture (Nouwen calls it relationship to God)

## Spine / Continuum

As the project aims to create a place of affirmation rather than isolation, so too it aims to re-interpret the relationship of building to exterior that speaks of connection versus disjunction. This is a response to the particular precinct, where the current condition of the existing building and portions of the south edge of St. Ann's are seen as rigid boundaries *walling off*, or preventing connection between street, park and historic precinct.

The starting point for the spine is the *reinterpretation of the wall*. The retaining wall is viewed as being *of the earth* — as an extension of *terra firma*, strength. This is manifest in the solidity of the wall forming a spine that supports the programmatic layers of the project and in the configuration *of the spine as of the earth*: non angular, non-linear.

Metaphorically the spine speaks of experience as a continuum, no longer viewed as a dichotomy or dualism of linear versus non linear.

At the upper level, the spine serves as a circulation corridor. It is re-interpreted / transformed along its length and vertically by experience of solidity versus openness. It is primarily viewed on this residential level as *cloister*, providing quietness through the play of light penetrating a solid and acoustical separation from the ground level. The exception to this is where the spine is penetrated at the entries.

## Contrast

At the ground level the spine reads primarily as a solid. Here it houses the service core, storage and other similar functions. Adjacent to the solidity of the retaining wall spine on the main level of the building is the circulation corridor. In contrast to the solidity of the spine it is characterized by light. As one moves to the residential level of the facility from the main level, one passes from the light flooded interior street to the cloistered circulation zone contained within the spine at this level.

The circulation core at the ground level is predominantly a space of potentiality. It may function as a 'back lane' or semi-private space, as users of adjacent ground level rooms have the option of experiencing the walls between the rooms and light corridor as a diffuse boundary and moving out into this area. The main level rooms have varying degrees of flexibility to diffuse boundaries at the public/private edges.

### Conceptual Model

The conceptual model illustrates these key points:

- The solidity of the retaining wall / spine / core
- The changing response or transformation of this line:
  - dampening as it moves toward the day use / everyday / street grid
  - amplifying as it moves toward the residential use / park grid
- The nature of the boundary / boundaries between the spaces, as illustrated by the transparency, translucency and solidity of the materials.

Boundaries may be rigid, clear or diffuse boundaries, or variable, meaning the user controls the nature of the transparency of the wall.

### Gathering of Lights

While death is normal, in the sense that it happens to everyone, it is certainly not ordinary. Dying is an experience each person encounters once in a lifetime and is a journey into the realm of the unknown. The task of reconciliation to this journey touches all of those facing life threatening illness and / or loss of a loved one.

The 'Light Box' / 'Gathering of Lights' is not literally a box. It is a space defined by the translucency of cast glass, the light of memorial candles and the presence of water. An inverted roof allows rain to enter and collect in a pool. In fine weather, the pool will be still. During periods of rain (characteristic of the geographical coastal location) rain will

be funneled into the pool. This element of the project provides both shelter and exposure to nature. It is a reference to the paradox of our existence — the reconciliation of free will and being a part of eternity, a larger mystery over which we have not attained mastery.

The pool within the 'light box' feeds a pool in the urban court at the level of the building entry. This pool, in turn, feeds small irrigation channels that funnel water to the gardens of the courtyard - the trees and seeds of life.

The upper level of the 'light box' is physically impenetrable to the public. The public is denied direct access to this intimate realm which addresses the movement of reconciliation with life / nature / the greater realm beyond personal control. Yet the public is able to 'read' the experience in an implied way through the translucency of the walls / seeing the light above, the pool below, through hearing the water and via access at the courtyard level.

In honour of the cycles of birth and death, the five elements of nature are expressed in the project in the following way:

- Fire, in fireplace and candles
- Water, in the meditation pool and irrigation channels
- Earth, in the concrete solidity of the spine
- Air, in the opening windows and visual and physical access to outdoors
- Space, in the openness to allow for accessibility for wheelchairs and beds

### Endnotes

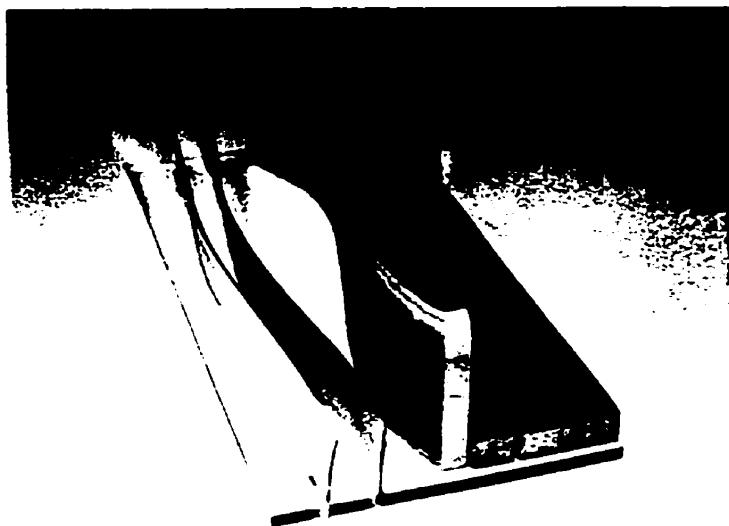
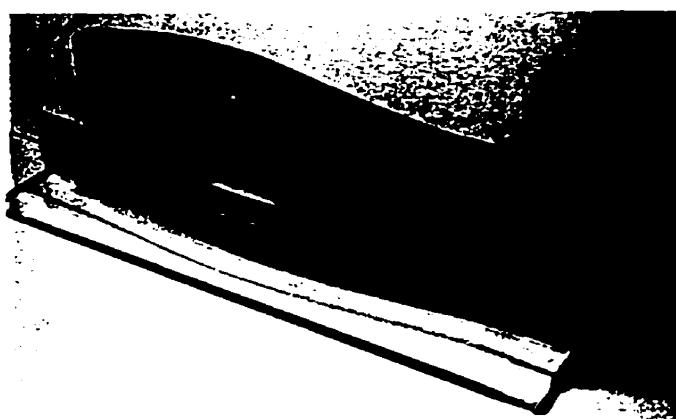
1. de Sola- Morales, Ignasi. 1996. p. 21.
2. Ibid. p. 22, 23.
3. 2. Ibid.
4. Ibid.
5. From *Present and Futures, Architecture in Cities*. Essay author unknown. p. 273
6. Nouwen, 1975.

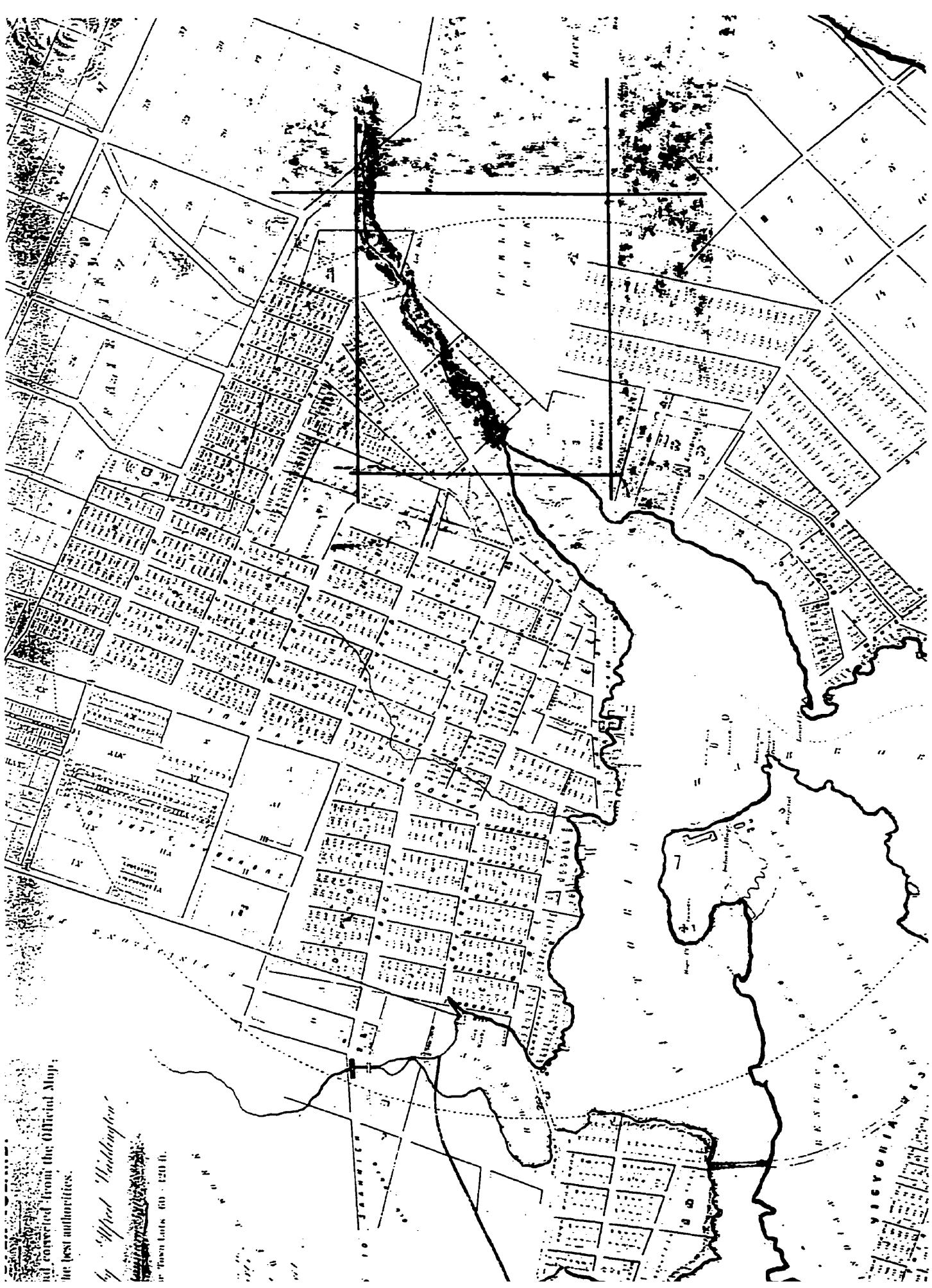
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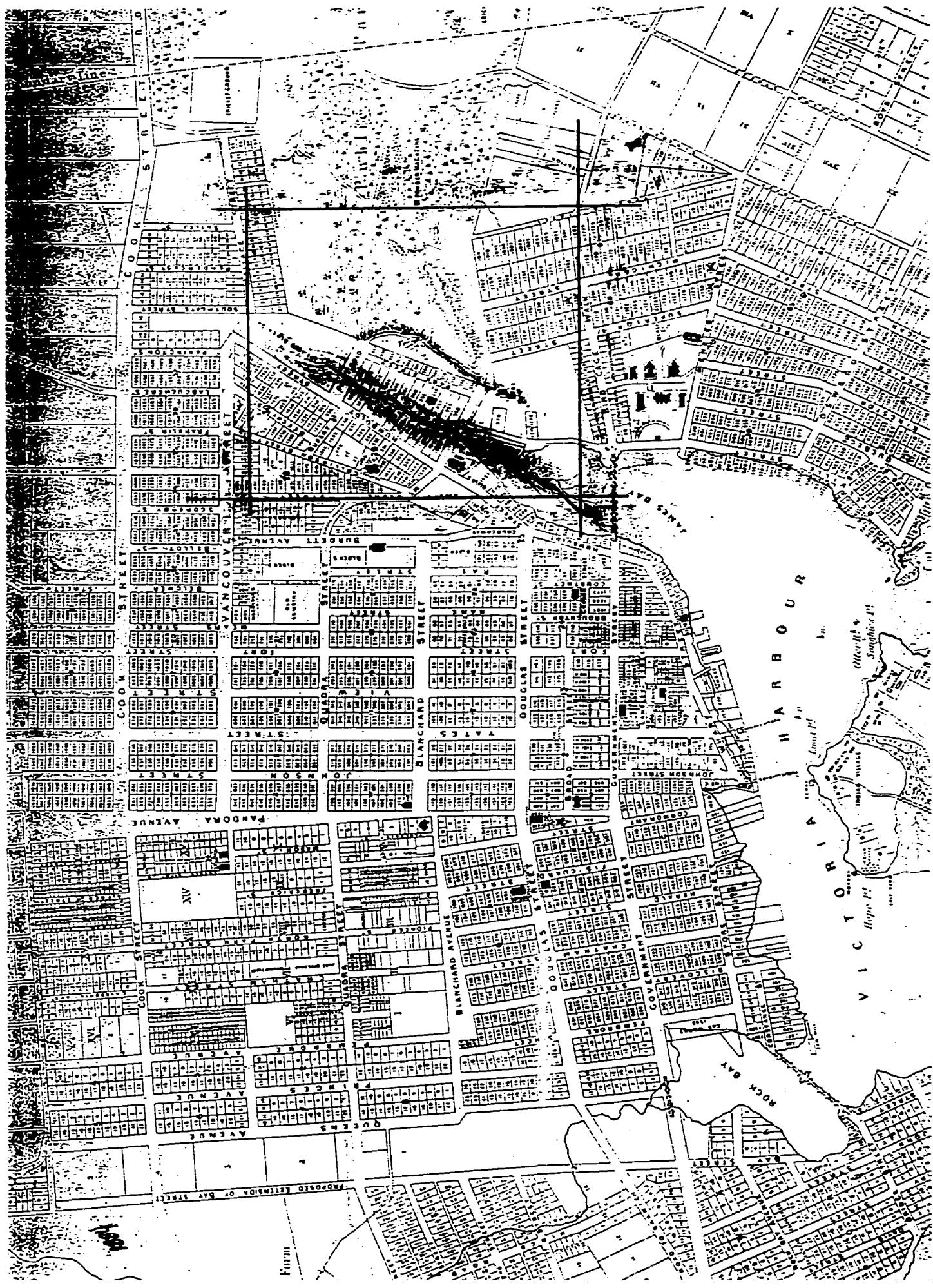
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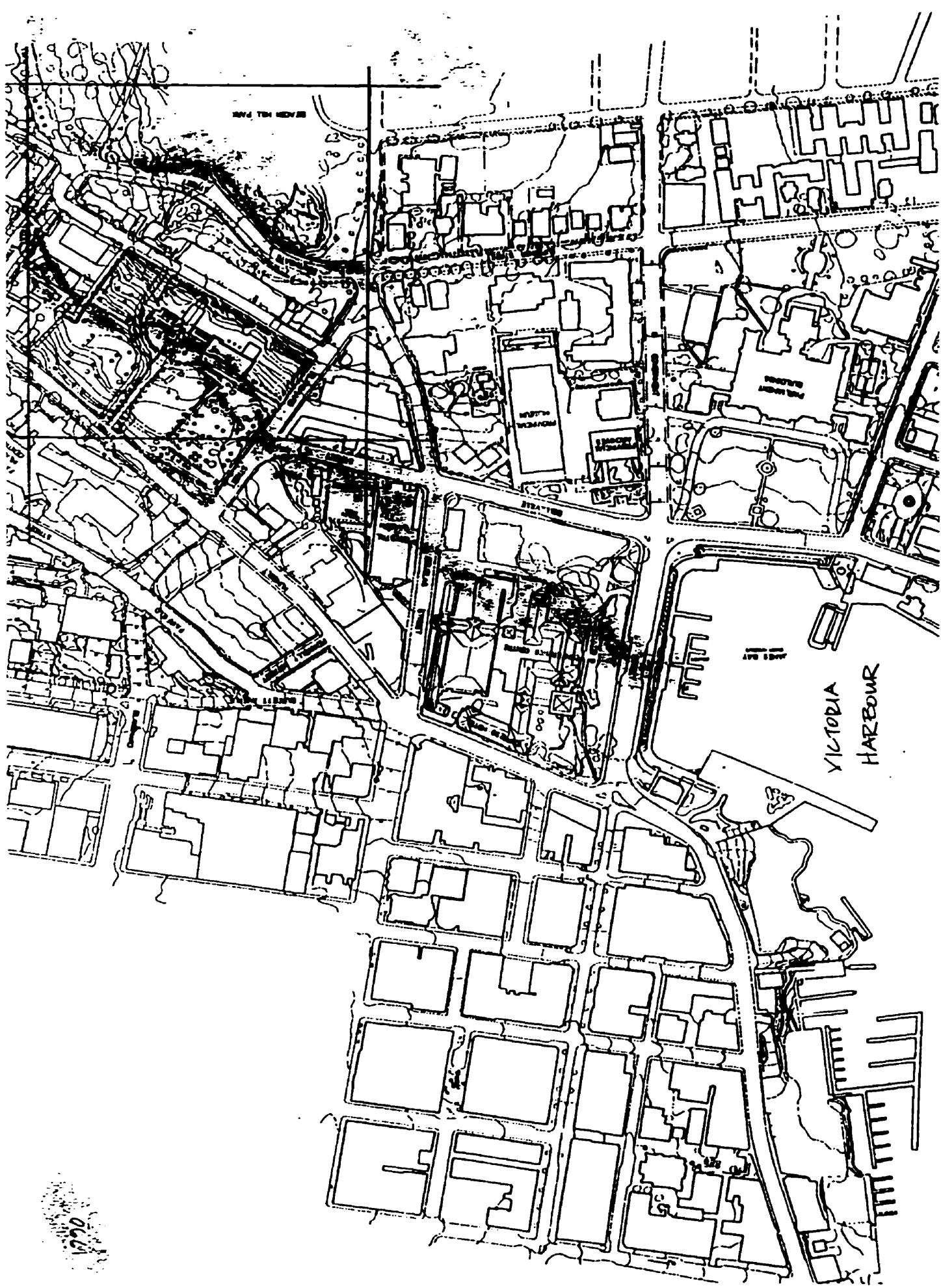


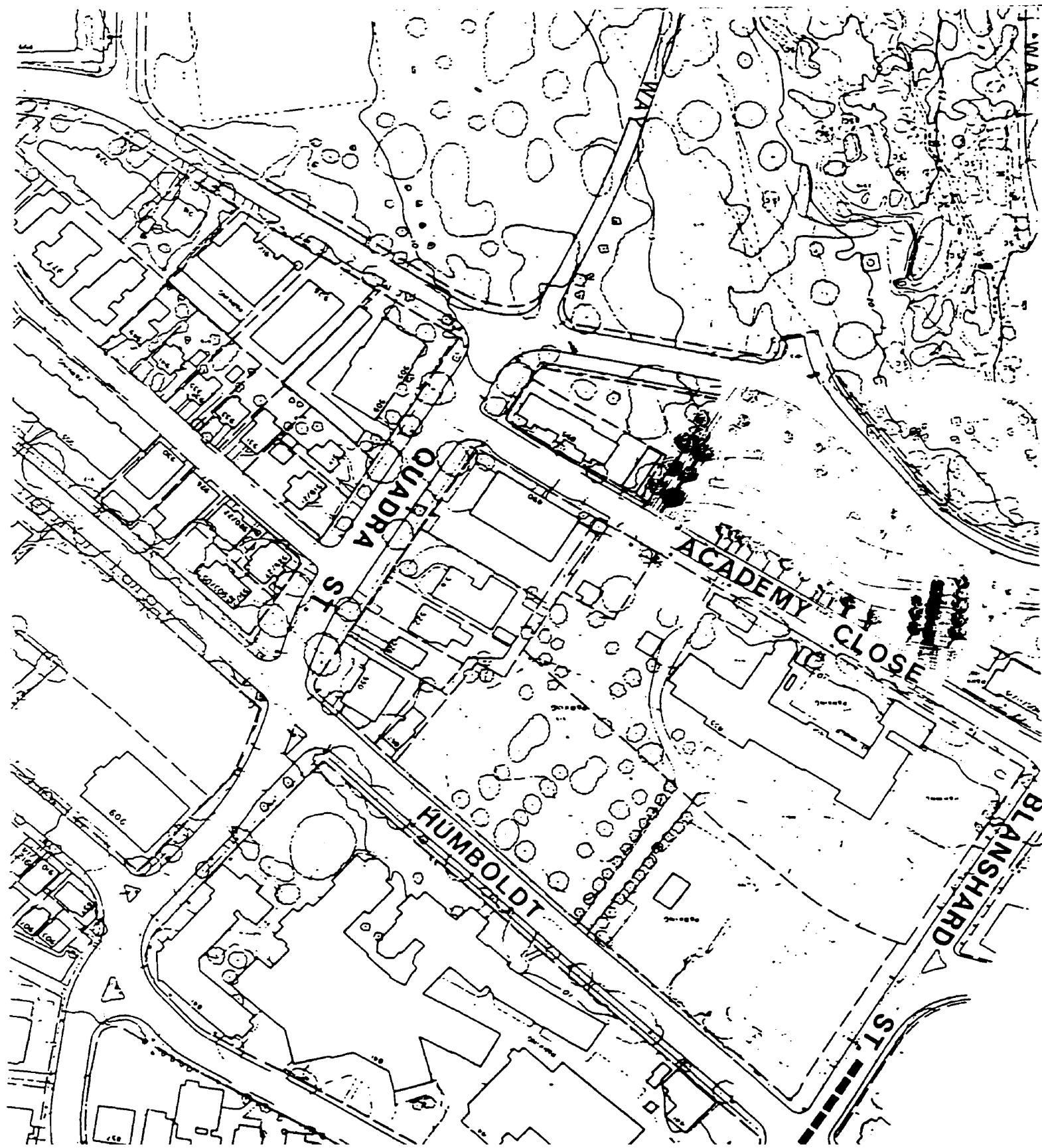
Conceptual Model





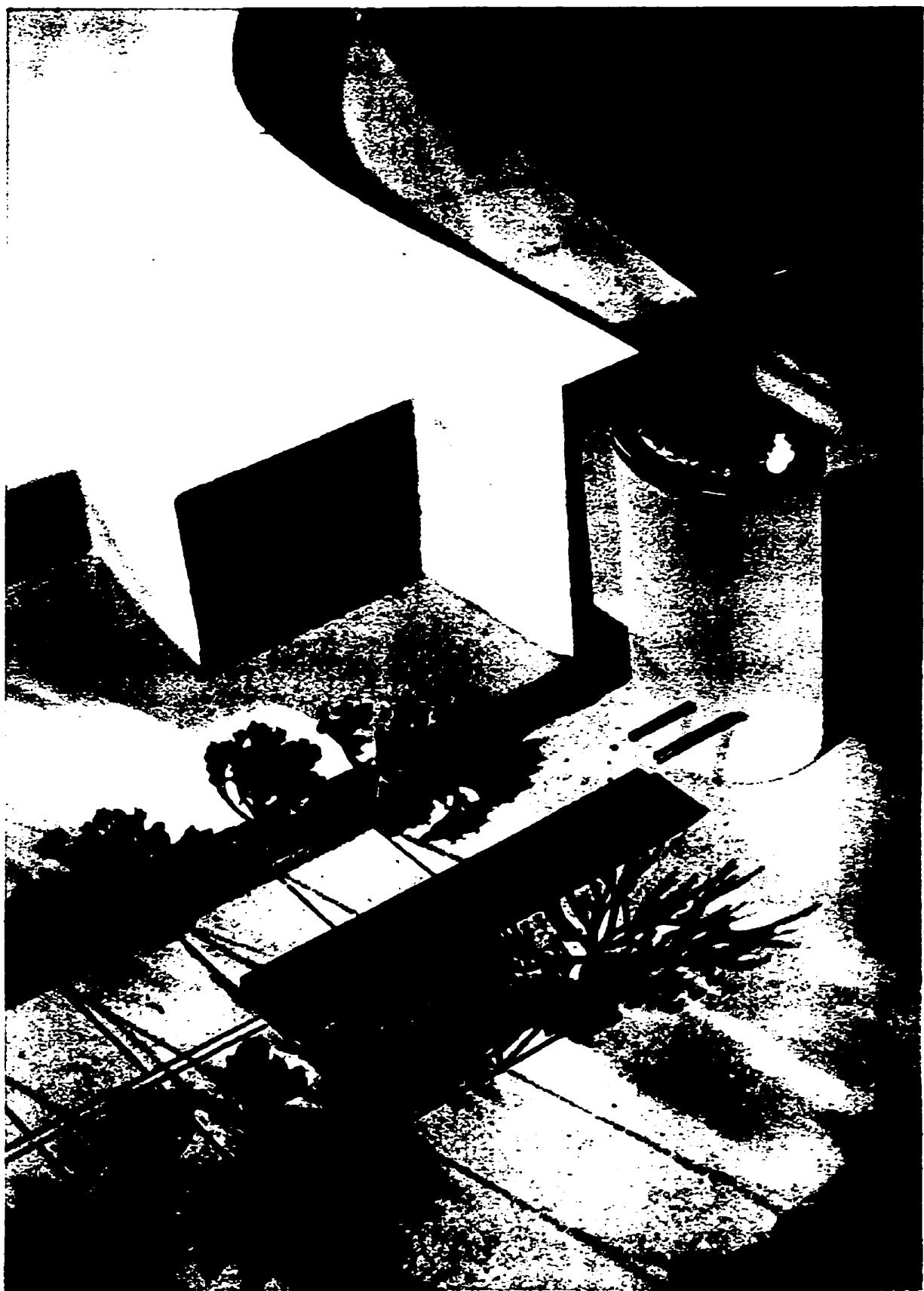


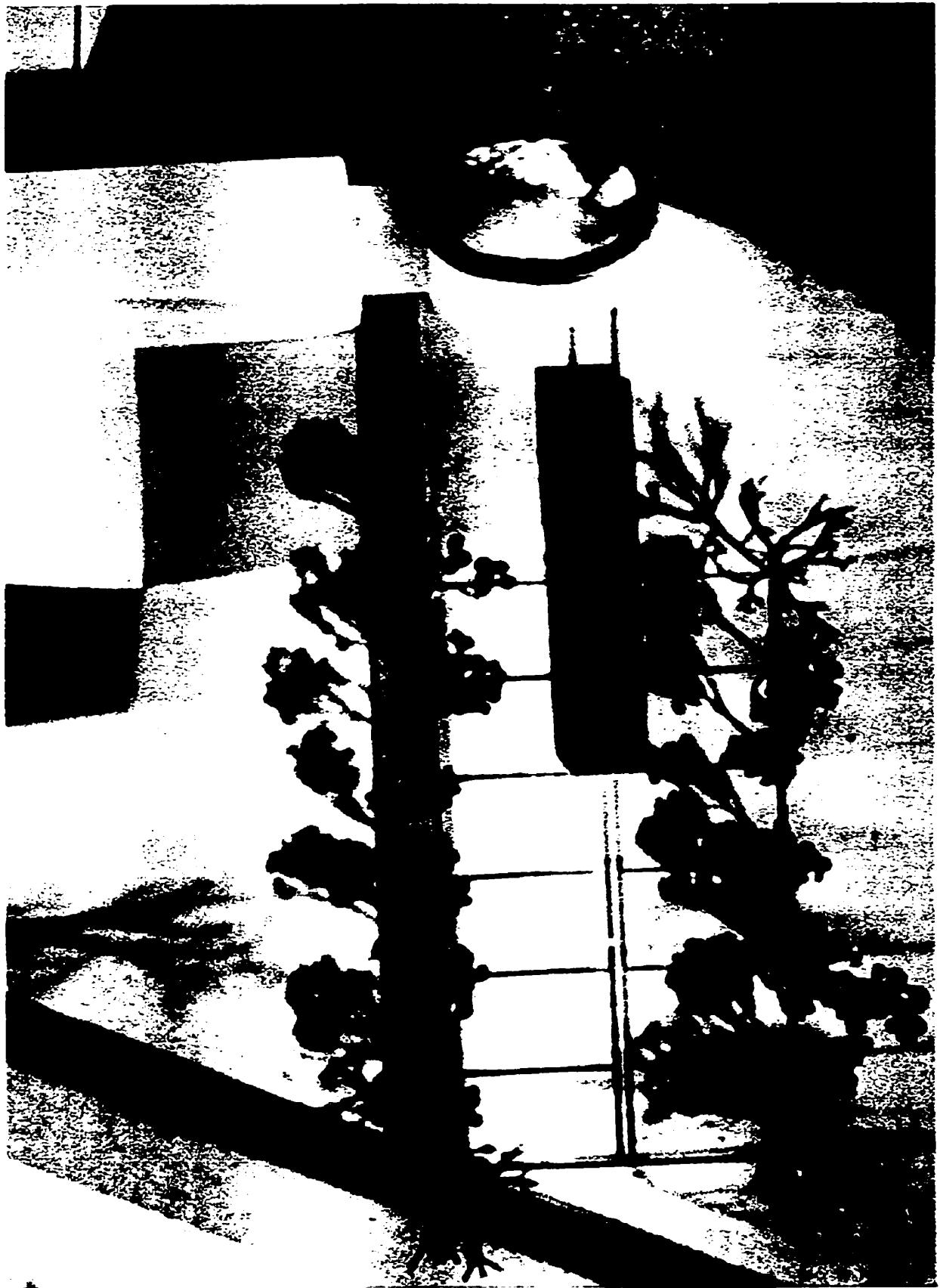








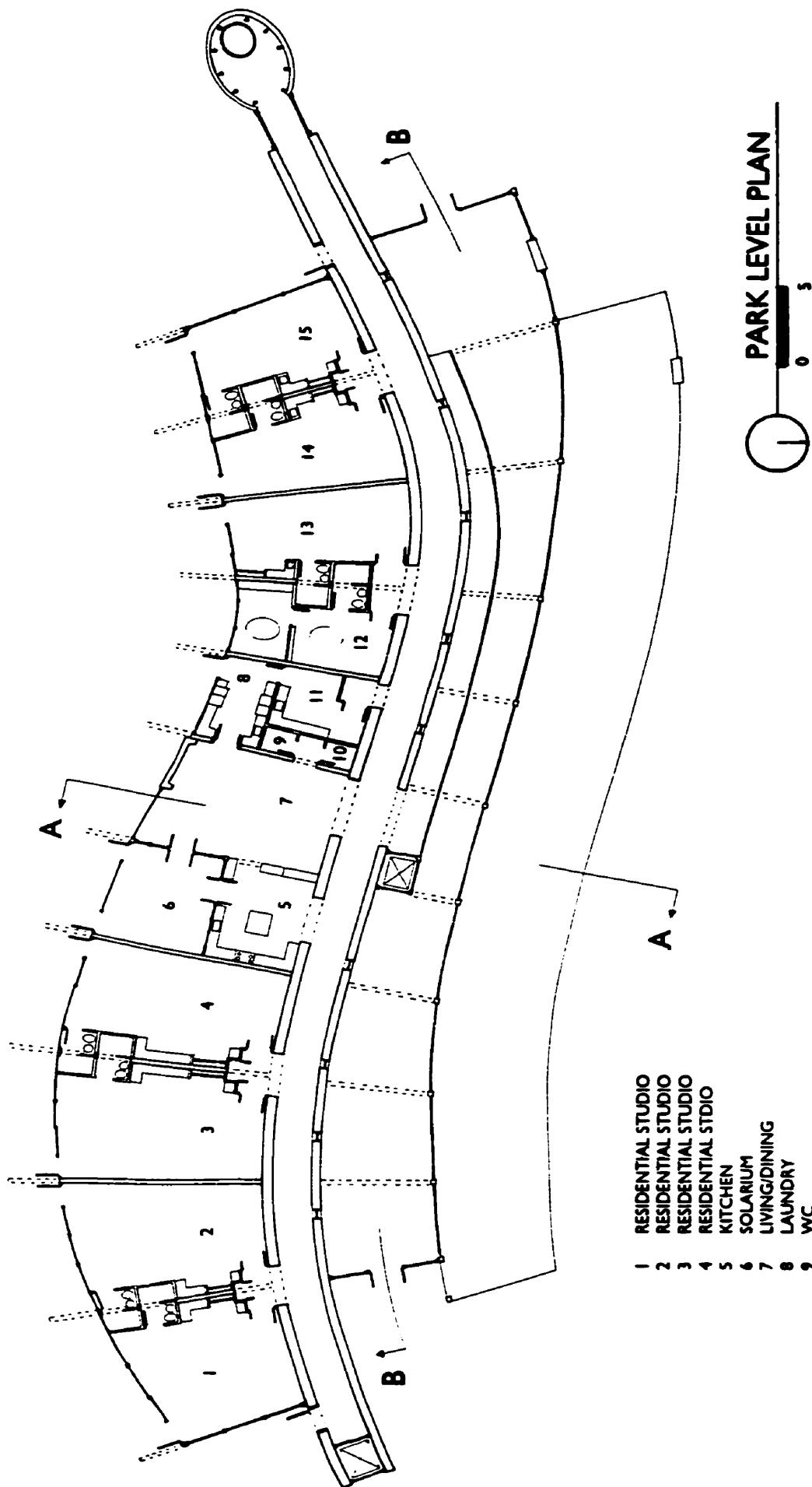








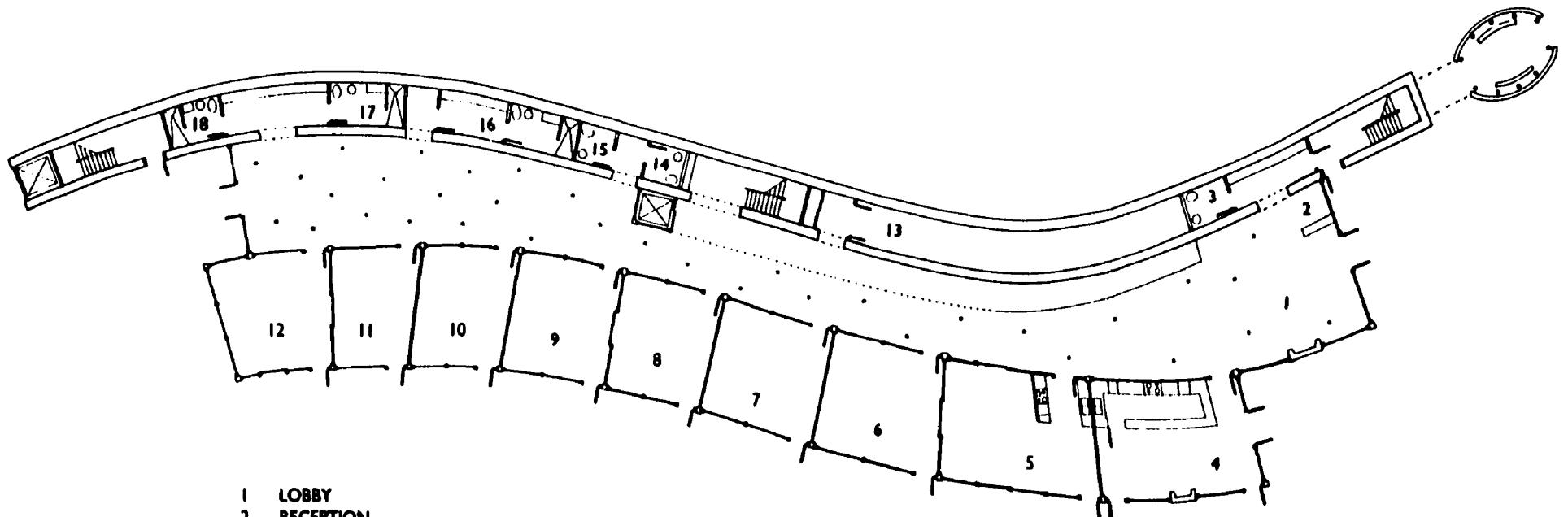




PARK LEVEL PLAN

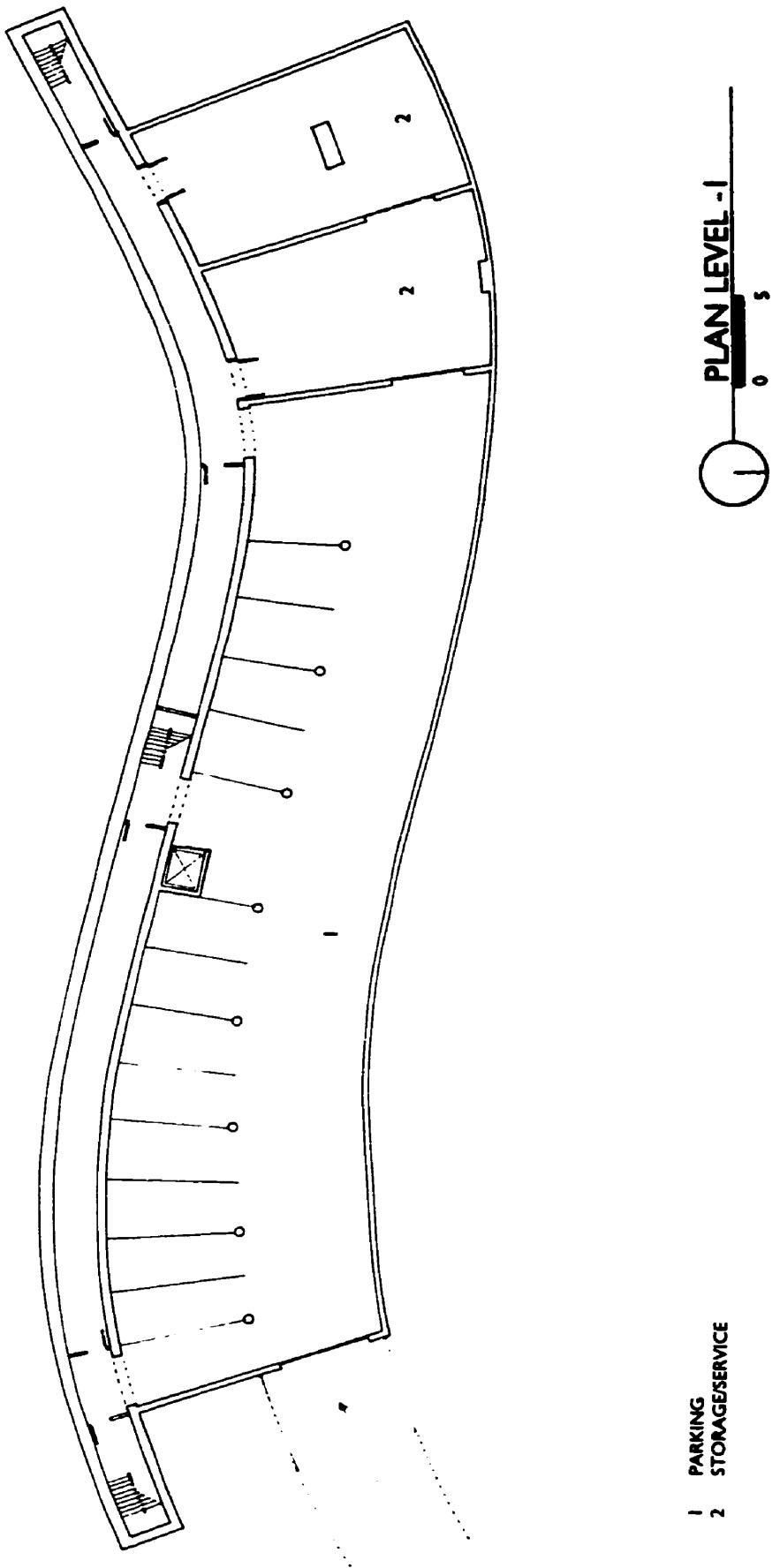


- RESIDENTIAL STUDIO
- 1 RESIDENTIAL STUDIO
- 2 RESIDENTIAL STUDIO
- 3 RESIDENTIAL STUDIO
- 4 RESIDENTIAL STUDIO
- 5 KITCHEN
- 6 SOLARIUM
- 7 LIVING/DINING
- 8 LAUNDRY
- 9 WC
- 10 WC
- 11 JANITOR
- 12 BATHING
- 13 RESIDENTIAL STUDIO
- 14 RESIDENTIAL STUDIO
- 15 RESIDENTIAL STUDIO

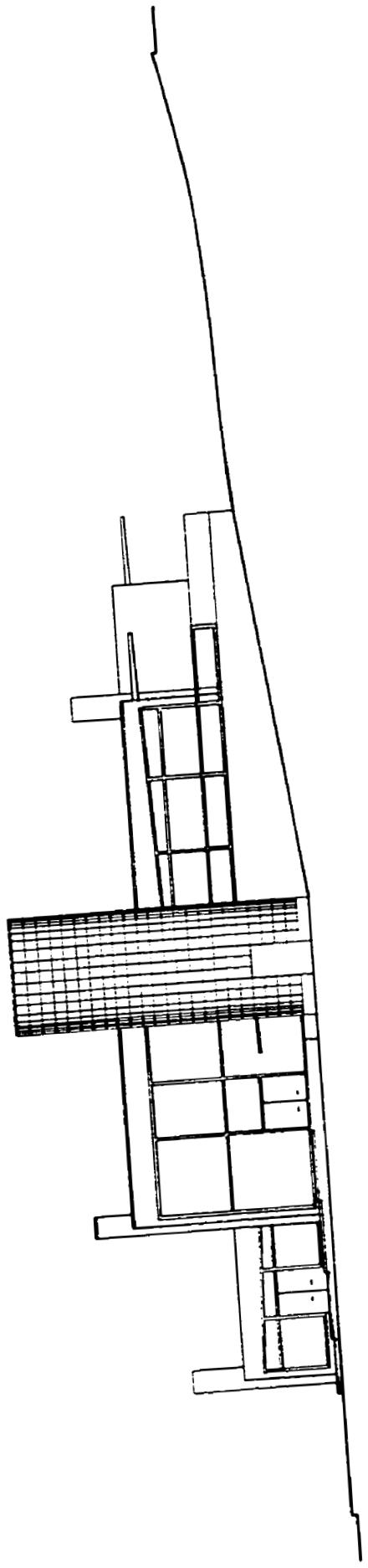


- 1 LOBBY
- 2 RECEPTION
- 3 WC
- 4 CAFÉ
- 5 ART THERAPY/DAY HOSPICE KITCHEN
- 6 CONFERENCE
- 7 POETRY & FICTION READING ROOM
- 8 VOLUNTEER AND STAFF OFFICE
- 9 RESOURCE CENTRE
- 10 STAFF
- 11 COUNSELLING
- 12 EXERCISE/MOVEMENT/DANCE/MUSIC
- 13 SERVICE
- 14 WC
- 15 WC
- 16 MASSAGE
- 17 SHOWER/CHANGE
- 18 SHOWER/CHANGE

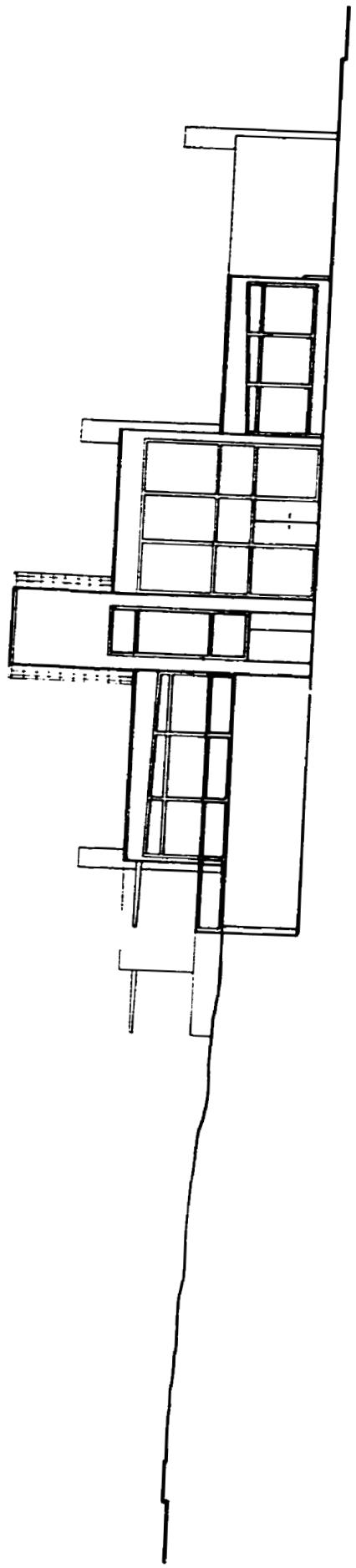
 STREET LEVEL PLAN  
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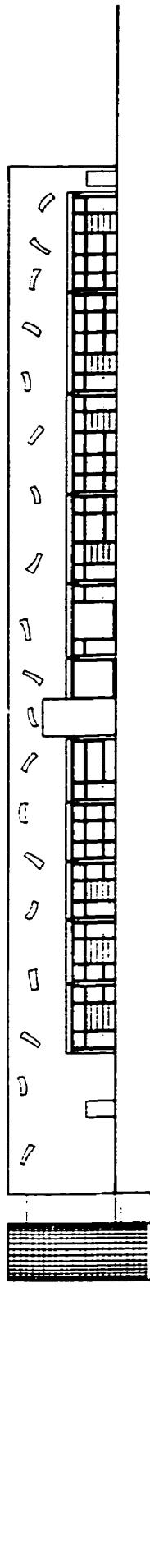
WEST ELEVATION



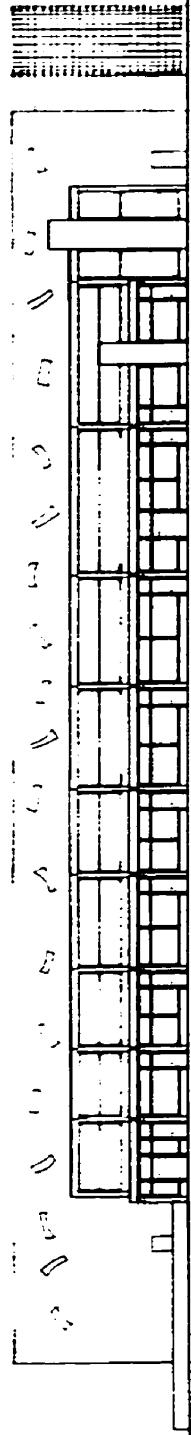
**EAST ELEVATION**



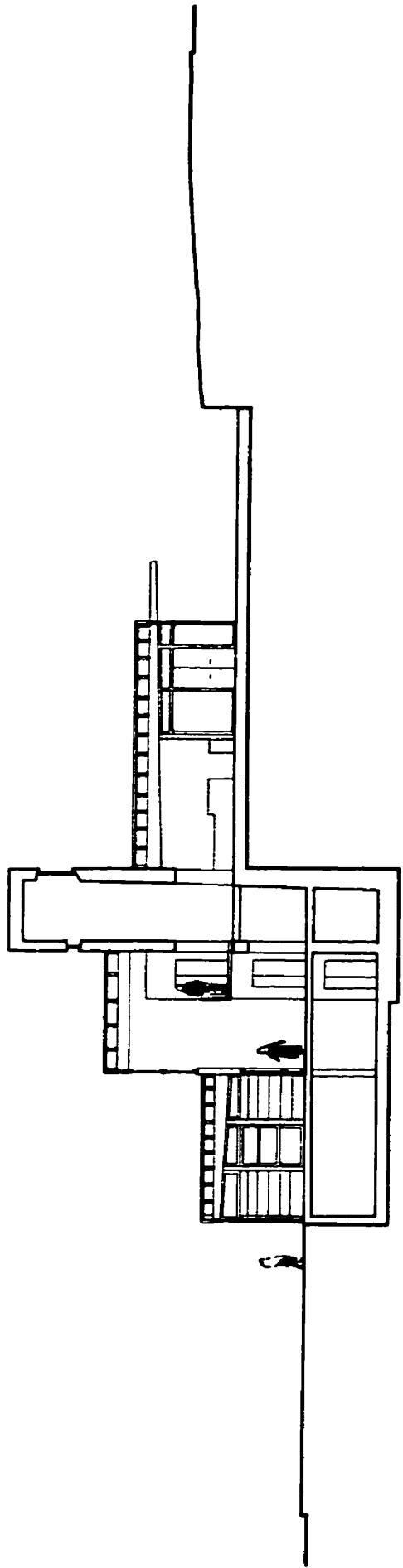
**SOUTH ELEVATION (PARK)**



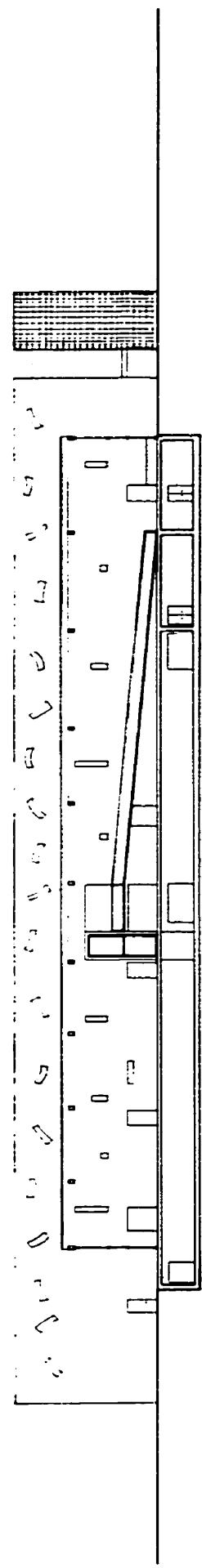
NORTH ELEVATION (STREET)



**Section AA**



**SECTION BB**



- Albertini, Bianca and Bagnoli, Sandro. (1988) *Carlo Scarpa:Architecture in Details*. Cambridge, Mass., MIT Press.
- Benedikt, Michael. (1988) *For an Architecture of Reality*. New York, Lumen Books.
- Bolen, Jean Shinoda. (1994) *Crossing to Avalon*. San Francisco, Harper San Francisco.
- Brookes, John. (1987) *Gardens of Paradise:The History and Design of Great Islamic Gardens*. London, Weidenfeld and Nicolson.
- Buckingham, Dr. Robert W. (1996) *The Handbook of Hospice Care*. Amherst, New York, Prometheus Books.
- Callanan, Maggie and Kelley, Patricia. (1997) *Final Gifts*. New York, New York, Bantam Books.
- Central Mortgage and Housing Corporation. (1992) *Housing for Elderly People; Design Guidelines*. Ottawa.
- De Beauvoir, Simone. (1966) *A Very Easy Death*. New York, G. P. Putnam's Sons.
- Eliade, Mircea. (1957) *The Sacred and The Profane:The Nature of Religion*. New York, Harcourt Brace Jovanovich.
- Frampton, Kenneth. (1985) *Modern Architecture;A Critical History*. New York, Thames and Hudson Inc.
- Frank, Arthur. (1991) *At the Will of the Body*. Boston, Houghton Mifflin Company.
- Goto, Takeshi, Editor. (Aug. 1997) Texts by Steven Holl in the magazine *Kenchiku Bunka*. Kenchiku Bunka 8, Tokyo, Shokokusha Publishing Co.
- Grof, Stanislav. (1994) *Books of the Dead*. London, Thames and Hudson.
- Grof, Stanislav and Christina. (1980) *Beyond Death:The Gates of Consciousness*. London, Thames and Hudson.
- Hense, Anton. (1966) *Le Courbousier La Tourette*. Paris, Bibliotheque des Arts.

- Hudson, Edward J. (1988) *The Hospice Response to Contemporary Western Attitudes on Death and Dying*. Toronto, University of Toronto Faculty of Social Work, Working Papers in Social Welfare Canada Publication Series.
- Ingersol, Richard. (Oct 1997) *Light Boxes*. In *Architecture* magazine.
- Killilea, Alfred G. (1987) *The Politics of Being Mortal*. Louisville, The University Press of Kentucky.
- Kubler-Ross. (1969) *On Death and Dying*. New York, Macmillan Publishing Company.
- Kushner, Harold S. (1981) *When Bad Things Happen to Good People*. New York, Avon Books Inc.
- Ley, Dr. Dorothy. (1994) *The Heart of Hospice*. Toronto, NC Press Limited.
- McCann, Kathryn and Durrett, Charles. (1988) *Cohousing: A Contemporary Approach to Housing Ourselves*. Berkley, Ten Speed Press.
- Manning, Margaret. (1984) *The Hospice Alternative*. London, Souvenir Press Ltd.
- Meade, Erica Helm. (1995) *Tell It by Heart: Women and the Healing Power of Story*. Peru, Illinois, Open Court Publishing.
- Miller, Marietta S. (1996) *Light Revealing Architecture*. New York, Van Nostrand Reinhold.
- Mullens, Anne. (1997) *Timely Death, What We Can Expect and What We Need To Know*. Toronto, Vintage Canada, a division of Random House of Canada.
- Nasar, Jack L., Editor. (1988) *Environmental Aesthetics: Theory, Research & Applications*. Cambridge, Mass. Cambridge University Press.
- Norris, Kathleen. (1993) *Dakota, A Spiritual Geography*. New York, Houghton Mifflin Company.
- Nouwen, Henri J. M. (1975) *Reaching Out: The Three Movements of the Spiritual Life*. Garden City, New York, Doubleday & Co.
- Pevsner, Nikolaus. (1976) *A History of Building Types*. New Jersey, Princeton University Press.
- Rando, T.A. (1984) *Grief, Dying, and Death: Clinical Interventions for Caregivers*. Champaign, Illinois, Research Press.
- Remen, Rachel Naomi. (1996) *Kitchen Table Wisdom, Stories That Heal*. New York, Riverhead Books.
- Rukeyser, Muriel. (1949) *The Life of Poetry*. New York, Currier Books Inc.
- Shim, Brigitte and Sutcliffe, Howard. (April 1991) Ravine Retreat in the magazine *Architectural Review*.

Simpkinson, Charles and Anne, Editors. (1993) *Sacred Stories: A Celebration of the Power of Story to Transform and Heal*. San Francisco, Harper San Francisco.

Sontag, S. (1990) *Illness as Metaphor and AIDS and its Metaphors*. New York, New York, Doubleday Publishing Group.

Stauffacher Solomon, Barbara. (1988) *Green Architecture and the Agrarian Garden*. New York, Rizzoli International Publications.

Stoddard, Sandol. (1978) *The Hospice Movement, A Better Way of Caring for the Dying*. New York, Vintage Books.

Tanaka, Tomoaki. (Aug. 1997) *A Gathering of Different Lights* in the magazine *Kenchiku Bunka*. Kenchiku Bunka 8, Tokyo, Shokokusha Publishing Co.

Taylor, Daniel. (1996) *The Healing Power of Stories*. New York, Doubleday Publishing Group.

van den Berg, Jan Hendrik. (1978) *Medical Power and Medical Ethics*. New York, W.W. Norton and Company.

Van Gennep,A. (1960) *Rites of Passage*. London, England, Routledge & Kegan Paul.

Walters-Passafaro, Irene M. (1998) *A Place for Healing*. Master's Degree Project, University of Calgary, Faculty of Environmental Design.

Webber, Craig A. (1994) *Dividing Lines: An Architectural Inquiry of Boundaries and Thresholds*. Master's Degree Project, University of Calgary, Faculty of Environmental Design.

Worden, J.W. (1982) *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner*. New York, New York, Springer Publishing.

- Cover Kripalu Centre for Yoga and Health, Lennox, Mass., Program guide. (Fall/Winter 1998/1999)
- Chapter Dividers Images: from Carlo Scarpa: *Architecture in Details* (see bibliography)  
Poetry: Joan Wagner
- Page 1 Time magazine. (October 12/98, vol 152, no. 15, page 91) Nicole Bengevino photo.
- Page 2 Top image: Steven Holl, Chapel of Saint Ignatius, from Kenchiku Bunka magazine.  
(August 1997, vol 52, no. 610, p. 56) Paul Warchol photo.  
Bottom image: from Co-Housing: A Contemporary Approach to Housing Ourselves, p. 80  
(see bibliography) McCamant and Durrett photo.
- Page 3 Time magazine. (October 12/98, vol 152, no. 15, page 78) Bob Sacha photo.
- Page 5 Image of St. Lucy by Francesco del Cossa c. 1470, from slipcover of *Woman as Healer*, Jeanne Achterberg. (1990) Shambala Press, Boston.
- Page 6 Book slipcover, see bibliography.
- Page 8 Time magazine. (October 12/98, vol 152, no. 15, page 79) Nicole Bengevino photo.
- Page 9 Time magazine. (October 12/98, vol 152, no. 15, page 78) Bob Sacha photo.
- Page 18 Time magazine. (October 12/98, vol 152, no. 15, page 91) Bob Sacha photo.
- Page 20 Time magazine. (October 12/98, vol 152, no. 15, page 86) Andre Lambertson photo.
- Page 24 Book slipcover, see bibliography.
- Page 26 Joan Wagner photo.
- Page 32a Joan Wagner photos.
- Page 34a Joan Wagner photos.
- Page 36a Joan Wagner photos.
- Page 38a Joan Wagner photos.

- Page 40a Joan Wagner photos.
- Page 45a Co-housing images from *Co-Housing: A Contemporary Approach to Housing Ourselves*, (see bibliography) McCamant and Durrett photos.
- Page 46a Images of Chapel of Saint Ignatius by Steven Holl from *Kenchiku Bunka* magazine, (August 1997, vol 52, no. 610, p. 56) Paul Warchol photo.  
Image of Chapel of Notre Dame du Haut, Ronchamps, France, Le Corbusier architect, from *Light Revealing Architecture*, p. 58 (see bibliography) Marietta Millet photo.
- Page 50 Author hiking the West Coast Trail, June 1998, Carla Termes photo.
- Page 52 Joan Wagner photos.
- Page 52a Aerial photo from British Columbia mapping services, Ministry of the Environment, altered by Joan Wagner.
- Page 53a Map from City of Victoria Archives, altered by Joan Wagner.
- Page 54 Joan Wagner photos.
- Page 55 Map from Sisters of Saint Ann Archives, Victoria, B.C.
- Page 56 Joan Wagner drawings.
- Page 58 Map from City of Victoria Planning Department, altered by Joan Wagner.  
Paper sketches, Joan Wagner.
- Page 60 Image left: from *Utne Reader*. (July/Aug. 91 vol 46, p.79) Gary Baseman graphics.  
Image right: from Kripalu Centre for Yoga and Health, Program guide, (Fall/Winter 1998/1999)

#### DRAWINGS AND MODELS SECTION

All images by Joan Wagner except maps.

Historic maps (hand coloured by Joan Wagner) City of Victoria Archives.

Contemporary map (altered by Joan Wagner), City of Victoria Planning Department.