



towards a society for all ages

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THE ALZHEIMERS PROJECT

A Natural Experiment
in
Fully-Challenged Aging



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WHAT WESTERN GOLD HAS TO SAY ABOUT AGING

Age is always an issue for actors because we are all experiencing difficulty with memory.

~actor

I've learned that I have to work harder to keep my brain alive. I am constantly challenging myself to learn new things and I spend time with people who think about things that really matter.

~actress

I retired five years ago because the theatre had lost its magic for me. I came out of retirement because I was so struck by this play, and I learned that I could and would perform again, but only if it was something worthwhile, something that made a contribution.

~actress



I think a lot of how we feel is due to the preconceptions we have about age that are self-fulfilling. Sure, there are times when you don't have much energy, but there are ways of getting around it and it doesn't take long to recover. It really is true that the creative spirit is a source of energy.

-actor

THE ALZHEIMERS PROJECT

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THE ALZHEIMERS PROJECT

INTRODUCTION

Background: The Socio-Political Context

During the twentieth century, medical science has succeeded in extending the human life span by almost 30 years, but society has generally failed to ascribe a legitimate social function to those added years. In the 60's and 70's, social demographers ominously predicted the graying of America. Viewing older people generally as disengaged, dependent, non contributing members of society, they forewarned of the inevitable increase in society's burden of caring for catastrophic numbers of elderly people.

Today, the graying of Western Civilization is a fact of life. In America, life expectancy has increased from an average of 47 years in 1900 to 75.5 for men and 78.9 for women in the 1990s. In this century, the change in life expectancy is greater than the change in life expectancy during the previous 2000 years. In 25 years, it is estimated that in the Northern Hemisphere, 1 in every 5 people will be over the age of 60. In North America, the number of people over 65 is expected to double by 2016.

While the numbers were growing, a second and much quieter revolution was taking place. The face of age was changing -- a new specie of *homo sapiens gerontis* was emerging that is not only long-lived, but also healthier, more active, more adventurous, more creative, better-educated, sexier, more vigorous, and fully alive than ever before. Furthermore, these long-lived people have adapted to catastrophic social change throughout an extended lifespan, and their rich experience can be a treasured legacy. Yet, at the end of the 20th Century, American humanist Thomas Cole claims that "old age remains a season without a purpose".

Briefly, as a social and political context for the Alzheimer's project, consider the good news, the bad news, and the major challenge of an

aging society. The good news is that the negative stereotypes just don't hold for the vast majority of older people today. In particular,

- older people are healthier and better educated;
- the wealthiest people are over 50;
- older people have more power by virtue of numbers;
- business has discovered the aging market, and there are more leisure opportunities than ever before.

The bad news is that the glossy, tabloid version of old age, aka the Golden Girls, represents "positive stereotyping" which is just as dangerous as negative stereotyping because it doesn't reflect reality and, in particular, the following major trends:

- decreasing funding for social and healthcare services;
- increasing caregiver burden;
- increasing incidence of disabilities and diseases associated with old age;
- alzheimers has reached epidemic proportion, and is expected to triple by 2031 to over 3/4 million people in Canada alone.

Furthermore, the wealthiest people have always been over 50. More to the point, many older people (especially women) are poor, and what they need more than social services and healthcare is meaningful work. However, mandatory retirement remains at 65 years and, unlike the United States, Canada has no legislation against age discrimination in the workplace. If your workplace is the stage, the reality is, *Old actors never retire, they just don't get any more challenging roles to play.*

Challenge of a New Age

The challenge of our time is to reconstruct the meaning of old age, to view the aging of society as the unprecedented triumph that it is and to envision possibilities for growth and productivity unprecedented and unrecorded in human history. We must begin by attacking the stereotypes and assumptions about old age and old people that are insidious and destructive, left over from another time. Nowhere is ageism more visible than in the performing arts.

The Company: *Western Gold*

The Western Gold Theatre Society, founded in 1994 by Joy Coghill, is a company of professional, senior performing artists. Its aim is to present outstanding theatrical productions that expand and enrich the lives of both artists and audiences; to provide role models for healthy productive aging; to stimulate creative thought and encourage fully challenged aging; and to demonstrate the place and value of seniors in the community.

In 1995, this group of mature professional artists from across Canada met to consider how best to continue to contribute their skills and talents to the theatre community and its audiences. Supported by expert coaches, their exploration of Shakespeare's *A Midsummer Night's Dream* emerged as an acclaimed success. The documentary that followed, "Courage to Dream", is a unique teaching tool, currently used in an SFU course, Education 351 - Teaching the Older Adult, as a provocative means of attacking ageism. This film masterfully impresses students with how life is a continuous process of recognizing one's limits -- and transcending them.

In 1996, the company explored new avenues with concert readings of Shaw's *Don Juan in Hell*, and the staging of a challenging new Canadian play, *Alice: A Play with Music*. In 1997/98, Western Gold expanded into the community with an outreach program for seniors that included concert readings, interactive learning sessions, and a drama class, and it was also during 1997/98 that the company undertook its most challenging piece of work to date, *The Alzheimers Project*. As one member of the cast described the challenge:

When you act, you work from your experience and I had no experience of dementia. My challenge was to take the moments of real frustration that I have when I can't remember something and add it to what I was learning about Alzheimers Disease.

-actor

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The Ultimate Challenge

In many ways, Alzheimers Disease (AD) is the ultimate challenge of our age and our time. Few medical conditions command so much attention and instill fear in so many people. Alzheimers is a neurological disease of the brain, which occurs in both men and woman as early as the 30s, 40s, and 50s, and affects 5% of people over 65 and 25% of people 85+. It is incurable, with no known cause, and prevention and cure are yet to be discovered. AD and related dementias affect over 300,000 people in Canada; and over 40,000 people in BC alone. If we consider that for every person who has the disease, perhaps 20 others (friends, nurses, doctors, volunteers, spouses, sons, daughters, cousins) are touched by it in some way, we could safely say that Alzheimer's directly affects the lives of 20% of the Canadian population. The rest avoid it either by accident or design, and most are terrified by the thought of it.

The Alzheimers Project was conducted in partnership with the Alzheimer Society of British Columbia and the Roundhouse Community Centre. It involved the commissioning of a distinguished Canadian playwright to develop a script in collaboration with *Western Gold* and the *Alzheimers Society*. The play, *Strangers Among Us*, was marketed to the general public, seniors organizations, the Alzheimers network of professionals and caregivers, and students of gerontology and the theatre.

Purpose and Objectives

The primary purpose of the project was to serve as a catalyst for bringing Alzheimers Disease forward for discussion and exploration.

Specific objectives were:

- (1) To showcase fully-challenged senior actors, thus attacking the myths and stereotypes of declining ability with age;
- (2) To educate the public about Alzheimers Disease, i.e., to demystify the disease, thus reducing fear;
- (3) To raise public awareness of the impact of the disease on its victims and their families;

- (4) To provide a healing experience for those touched by the disease and to share the burden of care
- (5) To entertain.

Project Evaluation

Purpose. The purpose of the evaluation was to assess the extent to which the objectives have been achieved by assessing (a) the impact of the play from the different perspectives of the various client groups in the audience (i.e., general theatre-going public, caregivers, healthcare professionals, and students), as well as (b) the impact of the experience on members of the company.

Method

- (1) To collect feedback from a population sample representing each client group through personal interviews and/or written responses to standard questions;
- (2) To interview (by phone) a sample of the company regarding the impact of the experience;
- (3) To summarize the feedback and highlight selected responses;
- (4) Based on an analysis of the responses, to offer recommendations.

Questions for the Audience

- (1) What was your general reaction to the play?
- (2) What did you like best?
- (3) Was there anything you didn't like?
- (4) Your recommendation: Who should see this play and why?

Questions for the Company

- (1) What was most challenging for you?
- (2) Did age (your own or others) affect your work in any way? If yes, how did you deal with it?
- (3) What have you learned about aging?
- (4) What have you learned about Alzheimers Disease?

Protocol. A random sample of the audience was obtained by distributing approximately 80 questionnaires through Simon Fraser University's Gerontology Research Centre network of students and staff and the Alzheimers Society of British Columbia. Respondents were asked to identify themselves as (a) theatre-goers; (b) caregivers; (c) healthcare professionals; or (d) students, and to identify their age as (1) young adulthood (20 to 40 years), (2) middle-age (40 to 60) or (3) late adulthood (60 to 80). Some surveys were followed up with interviews, and members of the company were randomly picked and interviewed by telephone.

RESULTS

Results describe the impact of *Strangers* on the audience based on the analysis of responses from 7 people who identified themselves as general public (3 middle and 4 late adulthood); 10 caregivers (2 young, 4 middle, and 4 late); 9 healthcare providers (1 early, 5 middle and 3 late) and 5 students (2 early, 2 middle, and 1 late). With 2 exceptions, all of the respondents were women. The impact of the experience on the players is based on an assessment of telephone interviews with four members of the company (2 men and 2 women) and the director. (Wherever possible, direct quotes are incorporated into the text, and represented by italics).

Impact of Strangers on the Audience

General reactions to the play. The general public's reactions were overwhelmingly positive, with the emphasis on the quality of the acting. Many people seemed particularly excited about seeing such mature actors. One retiree who describes herself as "a recycled archaeologist", was thrilled with the production and felt,

The actors were a breath of fresh air and I never once thought of them as being "old". I am getting so sick of older people being undervalued, and these actors were so good. I am a newly retired person coping with 'being put on the shelf'. It is what happens in our culture. I'm supposed to go out to a pasture and hit golf balls.

Family caregivers reacted most favourably to the authenticity of the portrayal of persons with AD and family members. One said, *"It was wonderful, especially the players -- they got every nuance just right, the expressions were right on, how they spent moments, hand movements were typical"*.

A young healthcare professional (who is also a parttime student) expressed her reaction this way,

I was profoundly moved by the play. I wept in joy and sadness, recognizing painfully difficult and intensely beautiful human connections. I wept because I live far away from my father and mother, and I was left to wonder about the importance of so many trivial concerns and tensions, when there is so little time for us to share.

What people liked best. What the general public appreciated most was the sensitivity (i.e., good taste and humour) with which the subject was presented, and especially the sensitive portrayal of the relationship between Michael and Gabriel. One said,

The very sadness could have been devastating but there was so much humour. So much was almost whimsical at times, as people groped to make sense of things.

Another said,

The interaction between the 2 main characters was so real and so beautiful. They were on the same wavelength even though their communication was impaired. There was a sort of love that she didn't have in her marriage, and I have talked to people who said those things really do happen.

Caregivers particularly liked the sensitive, authentic portrayal of relationships.

The interactions between Michael and Gabriel were very real to me because I had experienced something similar. Only my husband's companion was another man. They used to wander around together, holding hands, and they seemed to do a lot of things with pencils and paper. My husband told me, "Phyllis, you have to

remember, I am just a little boy" and that's how I saw it. His friend's wife didn't understand -- she caught them lying in bed together one day and she forbade her husband to see my husband ever again. And it was such a shame, because all he needed was a friend. If she had seen the play maybe she wouldn't have been so angry -- she suffered a lot.

Healthcare professionals particularly liked the accuracy of the portrayal of the disease. One said,

I loved how 'smart' it was -- it did not render a simplistic or sentimental view of Alzheimers. It provided a multi-layered, multi-perspective view. And it provided a sense of celebration of the human spirit.

Both caregivers and healthcare professionals acknowledged the benefits of increased public awareness, and the fact that the disease is now being talked about and more people are becoming aware of its effect on families, friends, and society.

Students (healthcare) mentioned many things, such as the different caregiver issues and relationships, the set, the humour. As one younger student said,

I liked how they incorporated humour, dance and music in portraying Alzheimer disease. I didn't expect to laugh, but there were some parts that were unexpectedly delightful. The dialogue was brilliant. We as the audience saw the reality of caregiving -- the frustration, the fear, and the tremendous capacity of people to love.

Drama students were excited to see older actors whom they admired, and they were excited by the possibilities it opened up for them. The idea that they could still be working in the theatre at 65 and 85 was something they had never considered. This demonstrates, quite dramatically, how people acquire limiting beliefs about old age at a very young age based on the older people whom they observe around them -- beliefs that limit their future possibilities.

What people didn't like. Criticisms from the general public were few, and they came primarily from people who saw the play when it first opened (including the critics). A number of people (notably those middle-aged) felt it was "scarey". The biggest critics were healthcare professionals, notably nurses, who didn't like the way the nurse was portrayed. One clinician expressed "*annoyance at most of the caregivers*"; another felt more work could be done on the accuracy of the portrayal and more could be made of the educational component. Interestingly, an Alzheimers staff person felt, "*The company emphasized the entertainment value of the play, whereas I would put greater emphasis on the educational value*". Another said,

The Director of the Alzheimers Society felt that the hardest critics would be the caregivers and she said, "*They filled the house at the benefit performance, and they gave it a standing ovation*". Furthermore, as one of the caregivers pointed out,

Anything we didn't like, the cast and director changed. That was part of their ongoing dialogue with the Alzheimers Society.

Impact of *Strangers* on the Company

The Alzheimers Project had a profound impact on members of the company, who are all aged 50+. They came to the play with their own pre-conceptions of aging and the inevitable declines and losses that might present problems in staging such an ambitious production. The biggest challenge was memory, since reduced memory is something everyone experiences. The commonly-held belief in the inevitable loss of memory is particularly frightening for those who make their living on the stage. Everyone who was interviewed mentioned the fear of declining memory -- one who retired more than 5 years ago was terrified that she wouldn't be able to remember lines as she used to. She was surprised and encouraged by her experience and she, like many others, expressed renewed confidence in their ability to continue to perform.

Preparing for the play required intensive personal research which included a visit to a care facility, where the company gained a deeper insight into this strange world. For some, their introduction to the disease was frightening. Many members of the cast were older than

victims of the disease whom they visited, which deepened their vulnerability and the awareness that "it could be me". One actor who had personal experience with a family member said she learned there is a level of communication that is very important even when most of the faculties are gone -- rather like communicating with a 6 month old baby. Another said, *"I have learned that the most awful thing about Alzheimers is that it seems to be a prison in which people exist, and they know they are there, but they can't get out"*. The actors expressed a greater respect for those with Alzheimers -- "respect for the human being who is still there." A respect that was clearly transmitted to the audience as their comments testify.

The company also learned that, to keep energy levels high, a longer rehearsal schedule is preferable -- the normal rehearsal schedule of 3 weeks was extended to 6 weeks. In addition, the company rehearsed for 6 hours a day, as opposed to the usual 8 hour days, and they worked 5 days/week, as opposed to 6 days/week. The intensity of the "normal" rehearsal schedule challenges energy levels, regardless of age. The director agreed that a less intensive rehearsal period was ideal, and should be considered for all productions, regardless of the age of the players.

The actors learned much more about aging than confidence in their own ability to remember lines and the benefits of an extended rehearsal period. They learned that age need not be a barrier to theatre work -- that simple adaptations can be made to ensure that the theatre continues to be enriched by and enriching for its most legendary professionals. They learned that mature actors can bring, by virtue of personal life experience, a depth and understanding of the human condition that adds richness and meaning to their work. And the director added:

I have enormous respect for these people. I have watched them on stage and admired their work for many years, and I worried that they would be hard to direct. But they were so knowledgeable, so generous, and so caring, they made it easy. I have never worked with a group like that before. It was a gift.

Summary

This summary is based on the responses of the audience and the company, filtered through the lens of a "critical gerontologist" (i.e., one who is concerned with identifying possibilities for emancipatory social change, including positive ideals for the last stage of life.) The Alzheimers project fulfilled the highest expectations of those who have been involved with the production. In summary, to what extent have the objectives been achieved?

- (1) To showcase fully-challenged senior actors, thus attacking the myths and stereotypes of declining ability with age;

Strangers presented a number of challenges for the company -- challenges that were unique to the subject matter and the factor of age increased the challenge. A number mentioned the particular challenge of representing an AD victim with compassion and understanding and not "going over the top". One said,

With other roles, you give the character your own interpretation. With the AD portrayal, you had to be convincing and authentic without making a personal comment. That is very difficult to do and required a lot of personal research and hard work.

Another felt the biggest challenge was technical:

The play was logistically very difficult because it was episodic and non-linear. Playing two characters, running off and coming back, sometimes not having a clue about what I was going to do next was very scary, but also stimulating because it was a challenge.

More than something to be overcome, age was a value-added feature of the production -- the audience got more than just outstanding performances. These "fully-challenged" senior actors were an inspiration, making a significant contribution to the theatre by virtue of their professional expertise and a unique contribution to society as powerful role models of vital aging in the context of the creative arts. The great sage Shankara is reported to have said, "We learn to grow old

by watching other people grow old". Western Gold has much to teach us all about the role of creativity in healthy aging and how to grow old with passion and purpose.

(2) To educate the public about Alzheimers Disease, i.e., to demystify the disease, thus reducing fear:

If you ask people of every age what they fear most about aging, they will either say "losing it" or "Alzheimers Disease". And those who are introduced to Alzheimers for the first time, say that it's scary. However, a little knowledge is, indeed, a dangerous thing, because it often creates debilitating fear and anxiety, and anxiety can cause memory loss, thus increasing the fear of actually having the disease in a dangerous feedback loop. Some researchers suggest that it is not age that causes memory loss, but the anxiety about losing it.

It is, therefore, critical to a healthy society that we demystify the disease and reduce the level of fear, particularly amongst older people who are the most vulnerable. People of all ages in the audience who already knew something about Alzheimers, expressed surprise that it wasn't scary. The recycled archaeologist summed it up this way:

It made me aware of how it affects people, but it also demystified the disease and we have to demystify it if we are going to talk about it. We had a chance to laugh, to cry and to talk about it. This is the beginning of a discourse that has to happen everywhere. It has to be discussed.

(3) To raise public awareness of the impact of the disease on its victims and their families:

The play was highly successful in raising awareness about the devastating impact of Alzheimers on its victims and their families. In fact, *Strangers* was a vehicle that gave public voice to the real experiences of caregivers, who applauded the authenticity of the portrayals. Even the critics learned about the impact of Alzheimers first hand from caregivers who reacted passionately to their negative criticism of the production and wrote letters to the editor.

The burden of caring for increasing numbers of disabled and dependent elderly people rests more heavily than ever before on family

members at a time when the traditional extended family is undergoing enormous change, variation, and stress. Typically, the burden of care rests primarily with women whose health and financial security are often compromised, and especially the daughters (as reflected in the play). It was also reflected in the composition of the audience -- many more women attended the play than men. Many men who were personally invited to attend the play, never showed up; and of the more than 30 people who filled out surveys, only 2 were men. Those who did attend, (many of them younger actors and students) were entranced by the play, appreciated the humour, and gained valuable lessons about the devastation of Alzheimers.

(4) To provide a healing experience for those touched by the disease, and to share the burden of care;

Gerontologists often refer to aging as a "woman's issue", because women tend to live longer, to be more financially dependent, and to assume greater responsibility for caregiving: it is noteworthy that the play featured two very different portraits of daughters as primary caregivers. However, Alzheimers has no gender bias -- men and women are affected equally, and the impact of the disease on family members can be just as devastating to both men and women. The play provided a healing experience and the gratitude of caregivers was expressed in many ways -- e.g., the Alzheimers Society received the following letter from a man who is learning to live again.

I was most adamant in confronting the playwright or director last night as media reviews had emphasized the humourous side of this affliction and in my own circumstance, after four years, I have yet to find any humour during this period of perenial pergatory. The performance last night borders on being beyond adequate description on how a subject has been handled with such compassion and humility that I lived every moment of the presentation and regretted preconceptions. This meritorious performance and the company are to be complimented on the way this subject was presented, and in closing I quote the playwright's notes "ordinary people who once laughed, cried and loved". That is all I could ever hope and pray for now.

Strangers provided more than just a healing experience for caregivers, but was also a venue for the Alzheimer's Society to get the word out about the latest medical information and the support that is available. In the final analysis, Alzheimers is everybody's business, and we need to get that message across to packed houses of people from every sector of society.

(5) To entertain:

Strangers has entertainment value, and stands on its own by virtue of artistic merit. There is always a tension between whether theatre is primarily to "entertain" or to "educate." In *Strangers* there is a delicate balance between the two. Poetic licence and humour is used to give a sense of hope and optimism to what is in reality a very depressing subject. Given its entertainment value and the many other value-added features -- e.g., changed attitudes toward aging, optimism and hope; education for the mind, healing for the soul, humour for stress relief -- the house should have been packed every night. Why wasn't it? Ironically, people stayed away for all of the reasons they need to see it. When people in a mental fitness class at a seniors' centre were asked why they didn't attend, one said, "*Why would we want to go to something that is so depressing? We don't want to spend precious time sitting through "this kind of stuff".*" Another said, "*This disease is what brought me to a mental fitness class. I have a fear of having Alzheimers, and when I dwell on it, I feel like I'm getting it.*" Clearly, the box office issue will require creative and innovative approaches and partnerships to get the very people there who could benefit the most.

RECOMMENDATIONS AND FUTURE DIRECTIONS

Anyone and everyone should see *Strangers Among Us*. The play should travel into the community, to different sites (seniors centres, care facilities, community centres, schools) and cities throughout the province (e.g., the Okanagan, Kootenays, Vancouver Island, Prince George). It stands alone on the basis of artistic merit and it has universal value, with a different appeal to different groups of people, in particular,

- Those who are not personally affected can appreciate the impact of the disease, reduce their fear of the unknown, and advocate for research and social action;

We hear so much about Alzheimer's that lots of people are scared, but you can't shut yourself out of it, because it can affect all of us. The play makes you think a lot about whether there is anything scientists or government could do to help alleviate the suffering.

- Students and all healthcare professionals and service providers (paid and unpaid) should see it for the educational value, and particularly to understand the caregivers' point of view. A number of professionals expressed an interest in a video as a teaching tool. Educational videos are available through the Alzheimer's Society that are more accurate and detailed in their information concerning the disease and its prognosis, but *Strangers* offers a different kind of education that goes beyond the clinical. As one nursing student put it,

The play also featured a nurse, who at one point, dismissed her glibness about Alzheimer as being an "occupational hazard". This really pointed out to me how easy it is for healthcare professionals to be desensitized to the plight of patients and caregivers after some time. This kind of insight really makes me think.

- Caregivers can benefit from seeing how others cope; and they can see themselves and experience a healing effect;

It's good for caregivers because they can relate and it is a good way to work through some of their grief. I couldn't laugh the first time I saw the play -- It's been 18 years for me -- my mother had the disease in the late 70's and it never leaves you -- it affects every part of your life and you never forget it.

- People with elderly relatives or friends gain knowledge and understanding. Seniors, themselves, who are particularly vulnerable to the disease have much to learn - as one said,

I went with the knowledge that it might be depressing, but you can't shut yourself out of it. I wasn't depressed by it. Lots of awful things can happen to people -- Alzheimers is just one of them.

Challenges for the Future

This play and this company have a message of hope that everyone needs to hear. *Strangers* must continue to reach audiences in the community, throughout the province, and across the country. One of the biggest issues is the box office issue. Government and private enterprise and insurance companies must see this play and support it. The launching of 1999, the International Year of Older Persons, is an ideal time to focus on Alzheimers Disease and to give this superb company of actors a strong role to play in building a Canadian Society for all Ages. And *Strangers Among Us* is a must for a gala evening at the World Congress on Aging in Vancouver, July 1-6, 2001.

Time and again, people who were touched in any way by the play (whether they were caregivers, actors, students, Alzheimers volunteers) said, "*I feel that I have been given a gift*". One of them was the director, who expressed fears that are commonly held by people of all ages.

I learned a lot about aging. I have always been terrified of aging, always saw it as a continuous process of losing everything, physical and mental abilities, sexuality. But I learned you don't lose everything and I learned how sexy older people are, and I am less afraid.

We have all been given a gift -- the gift of hope for a better future for people of every age and hope for a better old age for each and everyone

of us. We have also been given the opportunity to play a role in making the world a better place. Surely, this is what living longer is all about. We owe a debt to the spirit of Western Gold, and most especially Joy Coghill, founder of the Company, and Thor Arngrim, producer of the Alzheimers play, whose vision and courage has made it possible. *Western Gold* deserves continuing public and private support, as an enterprise that exemplifies healthy productive aging and what it *really* means to be a society for all ages.

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ALZHEIMERS PROJECT, *STRANGERS AMONG US*

FEEDBACK FROM THE AUDIENCE

NAME: _____ (optional)

AGE: (please check one)

- _____ 20 to 40 (young adulthood)
 _____ 40 to 60 (middle age)
 _____ 60 to 80 (late adulthood)
 _____ 80+ (old age)

WHO ARE YOU? (may check more than 1)

- _____ (1) Caregiver (family, friend, neighbour, volunteer)
 _____ (2) Healthcare Professional (nurse, doctor, LTC)
 _____ (3) Student (nursing, gerontology)
 _____ (4) I enjoy live theatre
 _____ (5) other _____

FEEDBACK:

- (1) What was your (overall) reaction to the play?
 (2) What did you like best?
 (3) Was there anything you didn't like?
 (4) Your recommendation: Who should see this play and why?
 (5) Any other comments?

THE ALZHEIMERS PROJECT

EXECUTIVE SUMMARY

Age is always an issue for actors because we are all experiencing difficulty with memory.
~actor

Challenge of a New Age. During the twentieth century, medical science has extended the life span by 30 years, but society has failed to ascribe a legitimate social function to those added years. Viewing older people as disengaged, dependent, non contributing members of society, gerontologists forewarned of society's burden of caring for catastrophic numbers of elderly people. The challenge of our time is to reconstruct the meaning of old age, to view the aging of society as an unprecedented triumph and to envision possibilities for growth and productivity unprecedented and unrecorded in human history. We begin by attacking the negative stereotypes, and nowhere is ageism more visible than in the performing arts.

The Company. The *Western Gold Theatre Society*, founded in 1994 by Joy Coghill, is a company of professional, senior performing artists. Its aim is to present outstanding theatrical productions that enrich the lives of both artists and audiences; to provide role models for seniors; to stimulate creativity and encourage fully challenged aging; and to demonstrate the value of seniors in society. In 1997/98, the company undertook its most challenging work, *The Alzheimers Project*.

The Alzheimers Project was conducted in partnership with the Alzheimer Society of BC and the Roundhouse Community Centre. A distinguished Canadian playwright was commissioned to develop a script in collaboration with *Western Gold* and the *Alzheimers Society*. With the play at its centre, the primary purpose was to serve as a catalyst for bringing Alzheimers Disease forward for discussion and exploration. Specific objectives were:

- (1) To showcase fully-challenged senior actors, thus attacking the myths and stereotypes of declining ability with age;
- (2) To educate the public about Alzheimers Disease, i.e., to demystify the disease, thus reducing fear;
- (3) To raise public awareness of the impact of the disease on its victims and their families;
- (4) To provide a healing experience for those touched by the disease and to share the burden of care
- (5) To entertain.

A Project Evaluation was commissioned to assess the extent to which the objectives have been achieved.

Method & Protocol. A random sample of convenience was obtained by distributing approximately 80 questionnaires through Simon Fraser University's Gerontology Research Centre network of students and staff and the Alzheimers Society of

British Columbia. Respondents were asked to identify themselves as (a) theatre-goers; (b) caregivers; (c) healthcare professionals; or (d) students, and to identify their age as (1) young adulthood (20 to 40 years), (2) middle-age (40 to 60) or (3) late adulthood (60 to 80). Some surveys were followed up with interviews, and members of the company were randomly picked and interviewed by telephone. Feedback was analyzed and summarized, and recommendations made.

Questions. Members of the audience were asked: (1) What was your general reaction to the play? (2) What did you like best? (3) Was there anything you didn't like? (4) What are your recommendations? Who should see this play and why? Members of the company were asked: (1) What was most challenging for you? (2) Did age (your own or others) affect your work in any way? If yes, how and how did you deal with it? (3) What have you learned about aging? (4) What have you learned about Alzheimers Disease?

Results. The Alzheimers project fulfilled the highest expectations of those who have been involved with the production.

(1) To showcase fully-challenged senior actors, thus attacking the myths and stereotypes of declining ability with age;

Strangers presented challenges unique to the subject matter and the factor of age increased the challenge. A number mentioned the challenge of representing an AD victim with compassion and understanding. Another mentioned the technical challenge the play presented due to its episodic and non-linear structure: as one actress described it, *"Playing two characters, running off and coming back, sometimes not having a clue about what I was going to do next was very scary, but also stimulating because it was a challenge.* More than something to be overcome, age was a value-added feature. These "fully-challenged" senior actors were an inspiration, making a significant contribution as powerful role models of vital aging in the context of the creative arts.

(2) To educate the public about Alzheimers Disease, i.e., to demystify the disease, thus reducing fear:

If you ask people of every age what they fear most about aging, they will either say "losing it" or "Alzheimers Disease". And those who were introduced to Alzheimers for the first time, say that it's scary. People who already knew something about Alzheimers, expressed surprise that it wasn't scary. As one older woman said, *It made me aware of how it affects people, but it also demystified the disease and we have to demystify it if we are going to talk about it. This is the beginning of a discourse that has to happen everywhere.*

(3) To raise public awareness of the impact of the disease on its victims and their families;

The play was highly successful in raising awareness about the devastating impact of Alzheimers on its victims and their families. In fact, *Strangers* was a vehicle that gave public voice to the real experiences of caregivers, who applauded the authenticity of the portrayals. Even the critics learned about the impact of Alzheimers first hand from caregivers who reacted passionately to their negative criticism of the production and wrote letters to the editor.

(4) To provide a healing experience for those touched by the disease, and to share the burden of care;

Gerontologists often refer to aging as a "woman's issue", however, Alzheimers has no gender bias -- men and women are affected equally, and the impact can be just as devastating to both men and women. The gratitude of caregivers was expressed in many ways, in writing, phone calls to performers and the society, in the surveys and interviews. *Strangers* was also a venue for the Alzheimer's Society to get the word out about support that is available. In the final analysis, Alzheimers is everybody's business, and that message needs to be heard by people from every sector of society.

(5) To entertain;

Strangers stands on its own by virtue of artistic merit. Given its entertainment value and the many other value-added features, the house should have been packed every night. Why wasn't it? Ironically, people stayed away for all of the reasons they need to see it. "*We hear so much about Alzheimer's that lots of people are scared, but you can't shut yourself out of it, because it can affect all of us. The play makes you think a lot about whether there is anything scientists or government could do to help alleviate the suffering*". Clearly, the box office issue presents a major challenge to the creativity of this extraordinary company.

Challenges for the Future. This play and this company have a message of hope that everyone needs to hear. *Strangers* must continue to reach audiences throughout the province, and across the country. Government and private enterprise and insurance companies must see this play and support it. The 1999 International Year of Older Persons, is an ideal time to focus on Alzheimers Disease and to give this superb company of actors a strong role to play in building a *Canadian Society for all Ages*. And *Strangers Among Us* is a must for a gala evening at the World Congress on Aging in Vancouver, July 1-6, 2001.

Many people touched by the play said, "*I feel that I have been given a gift*". One said, "*I have always been terrified of aging, always saw it as a continuous process of losing everything, physical and mental abilities, sexuality. But I learned you don't lose everything and I learned how sexy older people are, and I am less afraid.*" *The Alzheimers project offers* a gift of hope for everyone -- hope for a better future for people of every age and hope for a better old age. Everyone associated with this production has also been given the opportunity to play a role in making the world a better place. Surely, this is what living longer is all about. We owe a debt to the spirit of *Western Gold*, exemplified in Joy Coghill, founder of the Company, and Thor Arngrim, producer of the Alzheimers play, whose vision and courage are a source of great inspiration. *Western Gold* deserves continuing public and private support, and many, many more curtain calls, as an enterprise that exemplifies healthy aging and what it *really* means to be a *society for all ages*.