

VOICE FOR CHOICE

THE LOOK ON THEIR FACES TOLD ME THIS WOULD BE PAINFUL

A true story from a DWD Member in BC

"The cancer is too far advanced. There is nothing further that we can do. It has simply spread too far into the brain. I am so sorry. It will not be an easy time for anyone."

I didn't believe that I was hearing these words for the second time in as many years. How can that be? I asked what would happen next. The look on their faces told me this would be painful.

Late in the summer of 2008, Dr. Alf Burt gave us the bad news. Shelby didn't have long to live. The cancer was virulent. She was already becoming disoriented, getting lost inside her own home. After sunset, she became fearful and wandered around the house, crying pitifully until she fell asleep from exhaustion. Her pain was becoming harder to manage. She didn't want to leave the house. She was starting to become incontinent, having accidents even in her own bed.

Those dark brown soulful eyes pleaded for us to help her. Shelby was a beautiful English Yellow Labrador Retriever, and very much a part of our family. Throughout her life, Shelby was faithful, protective, energetic and oh-so loyal. Near the end, she was afraid – Afraid – and humiliated by messing her bed and the area by the front door.

Dr. Burt came to our house the next day and Shelby was "put to sleep". One second she was here - the next she was not. No struggle, no whimpering. Her "family" was



DAD and Shelby

with her including that damn cat. After all, it was the humane thing to do. Who in their right mind would let their beloved pet suffer the pain and fear of cancer. Who hasn't had to "do the right thing" for their family dog or cat? Or gerbil for that matter?

Fast forward to the summer of 2010. Those same words. Brain cancer. Nothing we can do. We are so sorry.

Continued on page 2

WHAT SUE RODRIGUEZ STARTED, GLORIA TAYLOR IS DETERMINED TO FINISH

A look at the 3 main arguments in the court case for the right to die

The following analysis simplifies existing laws and the BC claim. The full claim filed by BC Civil Liberties, as well as updates and related information, can be found in the "follow the court challenge" section of our website. You'll find it under "Learn" on the main menu.

The BC Civil Liberties Association (BCCLA) has launched a challenge to the laws that criminalize medically-assisted dying. The BC Supreme Court was set to hear the lawsuit, brought on behalf of Gloria Taylor and three other individual plaintiffs, in November 2011.

The statement of claim makes three separate arguments. If the Supreme Court accepts even one of them, laws that criminalize medically assisted dying must be rewritten.

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Painful, continued from page 1

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Comments and feedback on any of the information in Voice for Choice are most welcome!

Dying With Dignity Canada is a member of:

The Canadian Hospice and Palliative Care Association

The Hospice Association of Ontario

The Bereavement Ontario Network

The World Federation of Right to Die Societies

ACE – The Advocacy Centre for the Elderly

Canadian Civil Liberties Association

Except this time it was my Dad. Dad was 78, rarely sick a day in his life. Dad didn't drink or smoke. He travelled extensively and was heavily involved in Rotary for 50 years. He had his own printing business for many, many years and was an environmentalist before it became in vogue after the hippie movement.

Dad had brain cancer. The operations in the past 12 months were unsuccessful. The cancer was virulent. Perhaps Dad knew better than we, as he had a Living Will drawn up.

"I don't want to be a burden to my family or to myself," he told me the day before the last operation. We were at a Blue Jays game.

"You are the oldest," he said. "I want you to do the right thing."

"I shall," I said. "Hey! The Jays just got a hit! Everything will be just fine."

Six weeks later, Dad died in the hospital in the middle of the night and no family was with him. For five of those weeks he could not talk, or move and he relied on the very kind nursing staff for everything, including cleaning him up after his accidents. His soulful blue eyes still reminded me of my promise to him at the ballpark.

The cancer did not kill him. It was a combination of the MRSA super bug and the withdrawal of food and water (VSED) according to the terms of his living will. It took more than 2 weeks.

My questions are simple. Who really died with dignity? Who was treated more humanely? Who would you rather have been?

I know my answers to these questions. I know that I want to have better end of life options than my dear old Dad had.

Rest in Peace you two.

CURL FOR CHOICE

On Jan. 3, 2011, Judy Folkard died after a painful struggle. Among her many passions, Judy believed that all Canadians deserve the right to a peaceful death. She worked joyfully through her life, organizing funspiels that, in 2010 alone, raised \$15,000.

One of Judy's wishes was that her husband, **Bruce Folkard**, would work toward ensuring that Canadians have options when the end of their lives approaches. In Judy's honor, Bruce took to a Guelph curling rink to carry on Judy's tradition of mixing funds and fun.

On Oct. 29 of 2011, Bruce and the many sponsors, curlers and volunteers from Guelph together raised over \$6,000 in Judy's memory at the first-ever Curl for Choice event. Beside the curling itself, a silent auction raised \$2,000. The big ticket item was a beautiful mink coat generously donated by long-time Guelph member and DWD advocate Josie Taylor.

The event helped bring the message of Dying With Dignity to curlers – not a crowd that we have ever specifically targeted – and heightened awareness of the issues in Guelph. Many of the curlers, sponsors and volunteers that Bruce recruited (or 'strong-armed' as Bruce says) have become members.

Thank you so much to all who participated.



Bruce Folkard and Wanda Morris with the big cheque – \$6200!!!

Gloria Taylor, continued from page 1

The first argument is made under the Constitution Act of 1867 which states that regulation and delivery of health services, the practice of medicine and regulation of patient-physician relationships are provincial matters. BCCLA argues that end-of-life treatment for individuals who are grievously or irremediably ill falls under these categories and should be regulated provincially (as a health matter) rather than federally (as a criminal matter).



The second argument is under Section 15 of the Canadian Charter of Rights and Freedoms. This section prohibits discrimination on factors including sex, age, ethnicity and physical disability.

Gloria Taylor notes that all Canadians have had the right since 1972 to end their own lives. She is deprived of this right, she notes, because she will not be able bodied when she wants to end her life. Consequently, she is suffering discrimination on the basis of her disability.

The third argument is under Section 7 of The Charter. This Section promises Canadians the right to life, liberty and security of the person. Here BC Civil Liberties makes three arguments:

1. Death is a part of life, so to deny an individual medically-assisted dying denies their right to life.
2. As a condition of liberty, citizens must have autonomy over their own decisions, especially regarding their own life and death. To deprive someone of the right to medically assisted dying is to deny them autonomy, and hence liberty.
3. If an individual does not have the right to make decisions regarding their own body, to exercise control over matters fundamental to their physical, psychological and social wellbeing, then not only has their human dignity been impaired but their right to security of person has been violated.

After the hearing judge of the BC Supreme Court renders her judgment, the losing party will have an automatic right of appeal to a panel of judges before the BC Court of Appeal. After a Court of Appeal judgment, the losing party would have the right to seek leave to appeal before the Supreme Court of Canada. If the Supreme Court of Canada grants leave, a panel of judges will decide the outcome of the case not only for BC but for all of Canada. If the matter is heard by the Supreme Court of Canada, a final decision in the case could come in approximately two years.

PERSONAL DIRECTIVES IN ALBERTA

John Warren, DWD Board Member

A Personal Directive in Alberta is similar to a “Living Will” or “Advance Care Directive” in other provinces. It enables another person to act on your behalf if you are incapable of making end-of-life decisions yourself. This can happen, for example, if you become unconscious, unable to speak or mentally incompetent.

To prepare a Personal Directive, you can obtain a form by contacting the nearest Office of the Public Guardian. Phone them toll-free in Alberta at 1-877-644-9992 or visit their webpage at www.seniors.alberta.ca.

The government form allows you to designate an agent to make decisions on your behalf and outline the decisions they can make for you, including those regarding health care and accommodation and other areas. You can also ask your lawyer to prepare the form for you.

Once prepared, the form must be properly witnessed. Your agent is not permitted to witness it. This ensures that you have not signed the form under any pressure from a person who could benefit.

To register that you have made a Personal Directive, go to the province of Alberta’s web site or mail the personal directive to the Office of the Public Guardian. When registered, any health provider in the province can access the website to identify your agent and learn how to contact them.

If you live in Alberta, a Personal Directive is vital to you, your family and the medical staff who will treat you.

IN HOSPITAL, UNABLE TO SPEAK. WHAT CAN YOU EXPECT?

Blair Henry, Ethicist and DWD Member

After learning about advance directives, a member wrote to say she was concerned about medical teams' efforts to find out a patient's treatment wishes. If she could hear and understand, but couldn't communicate, how would her medical team find out her wishes?

This is an important question, and a disturbing subject.

The medical condition the member was referring to is called aphasia, an impairment of language abilities that can range from difficulty remembering words to a complete inability to speak, read or write.

Aphasia can develop quickly as a result of a head injury or stroke, but in cases of brain tumors, infections and dementia, the progression can be much slower. To assess this condition requires clinical screening by a neurologist and extensive testing by a speech language pathologist.

How well is aphasia understood and what measures will a medical team take to better communicate with a patient in this condition? Without communication, will the team make decisions that lead toward end-of-life goals or a more chronic outcome?

Practice standards may vary by region and one can't assume the medical team will do everything possible to find out the wishes of a patient with aphasia. Larger trauma and stroke centres should

have resources to deal with aphasic patients. This does not mean smaller community hospitals don't have skills to work with aphasia.

In cases of aphasia which may not have been assessed, a medical team may ask a patient's relative or other substitute for a medical decision. The patient may be lying in the hospital bed fully aware and urgently wanting to communicate but is being ignored.

Pondering such a situation taps a primal fear, akin to being buried alive. It can be worse if the patient feels the case has not been properly assessed.

Family and friends are crucial in these situations. Often, a patient's family and friends are the first to recognize that the patient is trying to communicate.

When communication is limited, but not absent, the family and medical team can still use blinking of the eyes, or squeezing of the hand, to further comprehend a patient's wishes. Though full informed consent may be limited in that situation, the values of assent or dissent in simple terms can be a powerful message to help guide the direction of care.

Living wills and advance directives are still important. But you may want to make it crystal clear in the instructions section that any substitute decision maker should look carefully for alternative ways to communicate with you when you can't speak.

DWD Pays Tribute to Lance Morrison

Membership and Community Relations Director

Lance Morrison left Dying With Dignity this past October, but many will remember him for years to come.

After nearly a decade in Canada's fashion industry, Lance began working with Dying With Dignity, first as a volunteer in 2005 and later as an employee. While he will likely be best remembered for his caring and friendly nature, he also brought a strong dedication to expanding human rights to patients and families of those at the end-of-life.

Lance's decision to work for Dying With Dignity was influenced by his early life. He had first-hand experience with severe medical trauma as he underwent open-heart surgery at age 11, and later spent many weekends volunteering with palliative care patients.

In recognition of his service to Dying With Dignity, member and office volunteer Catherine Priske wrote the following tribute:



I met Lance when I decided to volunteer my time at DWD's National office in Toronto.

Lance was a joy to work with; he always had time for questions and frequent checks to see how we were doing. He had a wonderful sense of humor and sincerely cared for DWD's volunteers.

I know I speak for all office volunteers when I say how grateful we were for his support and appreciation, not to mention those marvelous Friday afternoon Starbucks snacks!! He worked hard to make us all feel comfortable, and was always appreciative of our efforts.

Lance might have started as my boss, but he went on to become a mentor and is now a special friend. I wish him the very best in all his future endeavours.

LIFE, DEATH AND THE KITCHEN TABLE

Martin Frith, DWD Member and former Client Support Program Director

Sundays in our house were always special. Besides my parents and four siblings, my grandfather, aunts and uncles, and friends often gathered around our large, fancy dining room table. This assembly had undertones of the sacred, though not in a religious sense. We needed a good reason to be excused from Sunday dinner. It was the only time of the week that we all gathered to be with one another.

My family would trade stories about what had happened to whom during the week, capturing the highs, the lows and the mundane in between. My parents and aunts and uncles might recall anecdotes about family no longer among us. This was my early introduction to “cracking the nut” of life’s complexities. It wasn’t so much about where the discussion ended, but more about the conversation path, appreciating differing viewpoints and how they were grounded in beliefs and values.



Something formative happened around that table. We gathered for more than food: we gathered for stories, laughter, arguments and to share joys and sadness. Topics covered the most controversial, such as euthanasia, war and religion. And the mundane, in the form of neighbourhood “updates.”

Talking about end-of-life issues represents some of the biggest decisions we make. This is true whether we are making decisions for ourselves or helping a loved one decide for themselves. A discussion at the kitchen table, perhaps over coffee, can help you wade through difficult choices.

Since the introduction of penicillin in 1940, the medical progress has been staggering. We are now more likely to suffer from chronic, rather than acute, disease. We now face an array of medical decisions and choices that our ancestors could never have imagined.

A kitchen table discussion is more than filling out an Advance Care Directive (historically referred to as a Living Will). The value is in understanding the wishes, values and beliefs of one another, and end-of-life desires. It’s not a discussion that takes place in one sitting. It’s a series of conversations that best occurs over time.

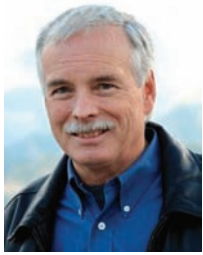
Many Canadians are unaware of their rights relating to end-of-life care. Most of these rights are protected by laws which are provincially administered. Every patient and family member should be aware of the following:

- **Substitute Decision-maker.** If you can no longer participate in medical decisions, you have the right to let your substitute decision-maker speak for you with the same authority as if you were speaking for yourself.
- **Pain and Symptom Management.** You have the right to relieve suffering with sufficient medication and vigorous pain management, even if such aggressive treatment may hasten your death.
- **Right to Refuse Treatment.** You have the right to refuse any and all treatment, even if the refusal might hasten your death. The only exception to this might be the provision of emergency care if you or your substitute decision-maker can’t make your wishes known.
- **Right to Discontinue Treatment.** Ethically and legally there is no distinction between discontinuing treatment and not having started in the first place. You have the right to discontinue treatment.
- **Right to Refuse Nutrition and Hydration.** In Canada, nutrition and hydration by tube is considered medical treatment. You can refuse or halt such treatment.
- **Right to Refuse Cardiopulmonary Resuscitation.** If you’re in a hospital, ensuring this right generally requires a physician to write a Do Not Resuscitate order. If you’re outside of hospital, some provinces now have a legal document called “Do Not Resuscitate Confirmation Form”.
- **Right to Change Doctors.** If you feel your physician is unwilling, or uncomfortable discussing your end-of-life options with you, you have every right to ask for another physician, or at least another opinion.
- **Right to Have Advance Care Directives Recognized.** Healthcare providers and your substitute decision-maker are legally bound to follow your directives.
- **Right to be Fully Informed of all Treatment Options.** Your physician is required to inform you of the risks and benefits of each option as well as the probabilities of success.

Many people feel uncomfortable talking about death. When people do not receive the end-of-life care they want, it is often due to lack of preparation. Many decisions are left to the end, when they may be too late to be honoured. Use your family’s table talk to discuss and clarify end-of-life wishes to prevent surprises at the end!

TWO NEW BOARD MEMBERS

Dying With Dignity Canada is pleased to welcome two new members to the Board. For bios and viewpoints of all our Directors, please see the About section of our website.



Jim Stephenson has a BS in electrical engineering and a joint PhD in business and economics from Stanford University. As a professor of business at UBC and SFU, he taught courses in policy analysis and information systems. Currently a computer consultant, Jim's past experience includes projects for government and corporate clients in Canada and around the world.

Jim has long been a supporter of thoughtful choices, and has not been afraid to speak out for them. In the 2009 BC provincial election Jim ran for the green party and received the most votes of any green party candidate.



John Warren emigrated from England in 1963 and worked as a Chartered Accountant in Calgary and Lethbridge. In 1983 he switched careers and became the first financial planner in Lethbridge and, in 1989, he and a partner founded Future Focus Financial Planners. John is now retired for which we are very grateful as he has turned

his time and attention not only to being on our Board, but also to speaking and writing for Dying With Dignity.

TWO NEW STAFF MEMBERS

While our office may be in need of repairs and a paint job, we've managed to do some major redecorating recently – in the form of new smiling faces. Here we'd like to introduce recent changes to our staff.



Margaret Johnston-Jones, the other fresh change at Dying With Dignity, is our new Client Support Program Manager. Margaret has both Bachelor of Science and Master of Divinity degrees. She is a member of the Canadian Association for Spiritual Care and the Ontario Association for Marriage and Family Therapy. Most

recently, Margaret was a multi-faith chaplain at Trillium Health Centre. She brings her passion for supporting those at end-of-life and her many years' experience in working with volunteers to this role.



Trudie Ross, our new Membership and Office Coordinator, came to Dying With Dignity with over 18 years of experience in office administration and management in the Not for Profit, Public and Private Sectors. The devoted mother of three has worked with BDO, one of Canada's largest accounting firms and spent

6 1/2 years with the Canadian Cancer Society. Trudie is well suited to this role as she not only loves interacting with volunteers and others, she also has a passion for planning, administration and organization.

MISSING POSTERS: STAPLES SOMETIMES AREN'T ENOUGH

Dianne Woodruff, DWD Member and Speaker

In September of 2011, John Warren told us of how posters he had put up in Lethbridge, Alberta advertising an upcoming speech were consistently torn down. In all, he had to put up posters 32 times to cover just six locations. It seems somebody – or some people – didn't take the time to understand the message, and didn't want others to either.

So, the following letter from Dianne L. Woodruff in Oakville, Ontario triggered an eerie case of déjà vu, and hinted at a possible answer.

In the fall of 2011, I was organizing "Straight Talk on Dying: know all your options." It's a public event offering useful information, personal stories and end-of-life options – not unlike those in which Wanda Morris, DWD Executive Director speaks about DWD issues.

I distributed posters and watched various places around town to see them on display. In one location, the posters were not up. I asked why. The organization said that

DWD's event was "controversial" and we were not offering equal time to the opposing view. So they would not put up the poster.

I explained that the talk was simply about our legal choices in health care.

"Why would you want to argue with the Charter of Rights and Freedoms?" I asked.

I was rewarded with a pause of intelligent second thought.

Then they re-considered assumptions about our event. Clearly, they thought it was about euthanasia, or even physician aid in dying, when it was actually about the choices and options to which every Canadian is entitled.

They posted the notice.

Our lesson: people do make assumptions without asking questions. Anticipate this. And don't be shy about checking back and clarifying the message if necessary.



ROYAL SOCIETY SUPPORTS ASSISTED DYING AND EUTHANASIA

In this much anticipated report, an expert panel of the Royal Society of Canada has strongly endorsed assisted dying and euthanasia for Canadians. Their support is unequivocal; they believe that informed Canadians should have the right to assisted dying or euthanasia. Committee chair Udo Schuklenk stated that terminal illness should not be a requirement as the term is too vague and doctors cannot give a precise prediction on length of life.

If the Federal Government refuses to amend the Criminal Code, the panel proposes that provincial prosecutors use discretion to avoid laying charges, or handle cases outside the traditional court system.

The full report or various summaries can be downloaded from the resource library section of our website. If you would like a copy and don't have Internet access, please call our national office and we will send it to you.

BEQUESTS AND SHARE DONATIONS MOVE US FORWARD

We are profoundly grateful for the recent bequests of **Nicole Sansfacon** and another donor who wishes to remain anonymous. We also want to acknowledge with gratitude the recent donations of shares by **Maurice Lalonde** and **Dr. Olga Kempo**. (Donating shares can be particularly tax effective as donors receive a tax receipt for the shares' market value but pay no taxes on any capital gains.) These gifts will enable us to continue and expand our critical work to ensure quality of dying and expand end of life choices for Canadians.

If you would like information about donating shares or making a planned gift to Dying With Dignity Canada, please contact our Executive Director Wanda Morris for more information.

THREE KEY CHANGES FOR BC ADVANCE DIRECTIVES

Rob Monterio, BC Lawyer and DWD Member

The following is abridged from a comprehensive document that details the changes in further detail. Please see our website for the complete, unabridged version – or call our national office and we'll mail you a copy.

As of Sept 1, 2011 three key changes were introduced respecting advance care planning in BC:

1. To maximise effectiveness, an Advance Care Directive (ACD) must contain an acknowledgement that refusal of healthcare is binding on Health Care Providers. Individuals should include the following wording:

"I know that a health care provider may not provide to me any healthcare for which I refuse consent in this Advance Directive."

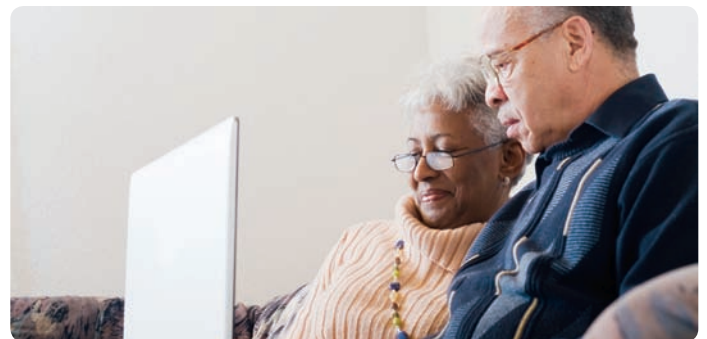
2. Substitute Decisions Makers are no longer required where clear direction is given in an ACD. Where such direction is given, a Substitute Decision Maker cannot over-rule an ACD's direction. Individuals are required to acknowledge this by including the following words in their ACD:

"I know that a person may not be chosen to make decisions on my behalf in respect of any health care for which I have given or refused consent in this Advance Directive."

3. Advance care directives or living wills made outside BC (but in Canada or other specified countries) will now be legally recognized in BC, providing they are legal in the jurisdiction where they were made.

Additional safeguards were also introduced to void an advance directive made fraudulently or through pressure, abuse or neglect.

Do you have an Advance Care Directive? All members receive an advance care planning package to help them create their Advance Care Directive. Please contact our national office if you'd like to join or if you're already a member and would like us to mail a planning package to you.



WORKSHOPS AND VOLUNTEER TRAINING CONTINUE APACE

Scheduled sessions in Ontario, BC and Alberta are shown below; call our National Office or see our website for more details. Would you like a workshop or training session in your area? We have found that it is important to have a local volunteer to ensure success – if you're willing to volunteer we'd love to work with you. Call or email our Executive Director Wanda Morris, to find out how you can help.

ALBERTA

Calgary, AB

February 4, 2012 / 10:00 – 11:30

Medically Assisted Dying and the Law

Unitarian Church of Calgary,
1703 1st Street N.W.

Sponsored by Unitarian Church of Calgary

Calgary, AB

February 4, 2012 / 1:00 – 2:30

Choice in Dying: Let's Look at the Facts

Unitarian Church of Calgary,
1703 1st Street N.W.

Sponsored by Unitarian Church of Calgary

BRITISH COLUMBIA

Vancouver, BC

January 7, 2012 / 9:00 – 4:00

Ambassador and Speaker Training*

Vancouver Unitarian Church,
929 49 Ave. W.

Sponsored by the Social Justice Committee of
the Vancouver Unitarian Church

Victoria, BC

April 28, 2012 / 9:00 – 4:00

Ambassador and Speaker Training*

Monterey Recreation Centre,
1442 Monterey Avenue

ONTARIO

Kitchener, ON

January 15, 2012 / 1:30 – 3:00

Medically Assisted Dying and the Law

First Unitarian Congregation of Waterloo,
299 Sydney Street South, Kitchener

Sponsored by First Unitarian Congregation
of Waterloo

Toronto, ON

January 13 – 14 / 2012

Intensive Training for Client Support Program Volunteers

Dying With Dignity Offices,
55 Eglinton Avenue East, #802
Members interested in applying to attend
should contact Margaret Johnston-Jones
at our national office

Toronto, ON

January 29, 2012 / 1:00 – 2:30

Medically Assisted Dying and the Law

Don Heights Unitarian Congregation,
18 Wynford Drive

Sponsored by Don Heights Unitarian
Congregation

Toronto, ON

February 3, 2012 / 11:00 – 12:00

Straight Talk on End of Life Options

West Scarborough Seniors' Club,
313 Pharmacy Avenue

Sponsored by West Scarborough Seniors' Club

*Session open to members only and pre-registration required.

Check out our website or contact our National Office at 1-800-495-6156 for details or to register.