

VOICE FOR CHOICE

JUST PRESS THIS BUTTON

The Last Days of a Man With No Choice

Rev. Shawn Newton, DWD Member and Speaker

“Just press this button,” the doctor said.

Looking at me – his eyes saying so much more than words ever could – he pointed to the button on the morphine pump that would increase the flow of the pain-killing narcotic to my friend Ben, who was in and out of a coma.

He said it again, making sure I understood.

“By pressing this button, like this,” he said, “we can increase the amount of morphine he’s receiving, putting him at ease until he passes. We’ll just keep increasing the amount to keep him comfortable until he slips away.”

The doctor said nothing about hastening Ben’s death. At least nothing direct. He was careful to focus the conversation on

palliative care. Yet, almost 20 years later, I’m convinced that this compassionate doctor was offering me guarded instructions about how to help bring my friend’s life to a relatively quick and quiet end.

Ben was 20 years my senior. He and I were training to be ministers, though everyone knew he would never make it. He had no time. AIDS had taken a toll on his body, and in the early 1990s, there was still relatively little defense against the ravages of the virus. Ben was a generation older than me. His was the generation of gay men hit first and hardest by the disease. Over the previous few years he had witnessed his closest circle of friends not merely decimated, but completely wiped out. When his time came, no one was left to take care of him. His friends were all gone. His family was



torn over whether to get involved given their upset and shame that he had AIDS. So, in my early 20’s, I became his primary caregiver.

Over the final year of his life, I organized care teams and meal delivery. I ordered his meds and scheduled a small army of home healthcare workers. I learned how to change IV bags and how to change a diaper. Little had prepared me for such enormous responsibility to another human being. And nothing had equipped me to make life and death choices for someone else, or to have a well-meaning doctor explain, with a nod and nudge, how I might help end Ben’s ordeal.

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WANDERING THE DARK HALLWAYS OF THE MIND

A DWD Member

As a long-time member of Dying With Dignity, my mother firmly believed everyone should have the right to die on their own terms. She spent several hours a week volunteering at a long-term care facility, delivering books to residents. I think she was trying to come to terms with her fears – she was particularly afraid of dementia.

When she was about 90, she started to suffer the fate she so dreaded. She became absent-minded and forgetful. For example, she would put a pot of water on the stove for tea and forget about it. I worried she would start a fire. With great effort, I persuaded her to move into a lovely retirement home. But her symptoms worsened and, within a year, we had to move her into a long-term care facility.

“She started to suffer the fate she so dreaded.”

My mother lived almost 99 years. For two or three years before she died, she went through an agonizing few hours every afternoon. She would lie in bed screaming and yelling, calling out for her older sister, Helen, who had been dead for decades. It was excruciating to hear. She was suffering exactly what she had vowed to avoid.

Toward the end of her life, my mother repeatedly said she wished she were dead. But she had no legal right to the life-ending assistance she sought. I dread wandering those same dark hallways that claimed my mother’s mind.

*DWD note: There are ways to shorten the time spent living with dementia. Advances in medicine have resulted in aggressive treatments that allow us to live through diseases and infections that would have been fatal for past generations. You can choose to deliberately forego such medical care. Simply specify in your **Advance Care Plan** the care you do and do not want in the event of dementia. For example, you can reject aggressive medical interventions – electing only to receive medication for pain control and symptom relief. No CPR, feeding tubes or other major life-sustaining treatments.*

You also have the right, through your substitute decision maker, to reject force feeding, flu shots, antibiotics, insulin and other life-prolonging medications. You can also forgo treatments and procedures such as dental work or blood tests which are often very traumatic for individuals with dementia.

NOTICE OF ANNUAL GENERAL MEETING

We will be holding our Annual General Meeting in Toronto on Sunday May 5th from 2:00 – 4:00. We time the AGM to follow our annual board retreat so that members have a chance to meet with board members from across the country. The AGM is a great time for members and supporters to hear about our recent activities and learn about plans for the future. This year’s AGM will feature a keynote address from Board Member and retired Physician Dr. Gregory Robinson. The AGM will be held at First Unitarian Church of Toronto, located at 175 St. Clair Avenue West, Toronto, Ontario M4V 1P7, parking is available.

ETHICAL INSIGHT

Case history Mr. B (Quebec):

Mr. B lives in a long term care facility. He is 79 and has advanced dementia. He no longer recognizes his family, and is becoming very frail and under-nourished, since caregivers find it increasingly difficult to spoon feed him. He has twice been hospitalized for aspiration pneumonia because it's difficult for him to swallow.

While competent, Mr. B made out an advance care directive (a Mandate) and automatically designated his wife as his primary decision maker, and his eldest son as alternate decision maker (Mandataries). The family didn't discuss the mandate, which was couched in very general terms. As a result, although the mandate gives them the authority, neither his wife nor his son are well prepared to make treatment decisions on his behalf.

Mr. B contracts pneumonia. In his already frail condition, it is likely

to prove fatal if left untreated. The physician attending him has requested a decision from his wife. Is Mr. B to be treated aggressively? Or is he to be allowed to die a natural death? Mr. B's wife understands that her husband has no quality of life left, but she feels unable to agree to a course of action that may lead to his death. She refuses to make a decision.

What is the physician to do?

Resolution: Mr. B's son is now the decision maker. Like his mother, he is in a highly emotional state and unsure what to do. He requests that his father's pneumonia be treated. Mr. B recovers. His dementia has progressed: he now exhibits aggressive and self-destructive behaviour and has had to be placed in restraints.

He can no longer take food by mouth and has a stomach tube inserted. Although his lungs are weak, the rest

of his vital organs are functioning and since he is now receiving nourishment, he is likely to survive in this condition for many years.

Looking back: A crucial component of an advance care plan is full discussion with those who will speak for you if you are unable to do so for yourself. It is helpful for your health care providers to understand your wishes for treatment, and essential that your loved ones are comfortable making decisions on your behalf. Our new Advance Care Planning Kit explains how to go about talking to your designated decision maker.

Mr. B is a resident of Quebec. Wondering what legislation concerning decision makers is in effect in your own province? Our new ACP Kit gives you the answer.

BRING OUT YOUR BANNERS!

Vancouver and Victoria – Come Out and Raise Your Voice for Choice

The hearing of the Attorney General of Canada's appeal of the BC Supreme Court ruling is scheduled to begin on March 4, 2013 in Vancouver.

This will be of great interest to the media. We do not doubt that The Euthanasia Prevention Coalition will be out with their fear-mongering signs such as "Assisted Suicide is Elder Abuse" or "Stop the Killing." **We can't let them control the media agenda!** This is an incredibly important time for all of us who are committed to the right to die with dignity.

Vancouver and Victoria residents are organizing events and teaming up with a coalition of folks from local

Unitarian and United churches; the Raging Grannies; BC Civil Liberties; Farewell Foundation for the Right to Die and others. All are welcome!

Come and Make Your Voice Heard!

Join like-minded folks for either of the rallies planned for the first day of the appeal hearing:

In Victoria on March 4, 2013 at the Legislative Building at 10:00 a.m.

In Vancouver on March 4, 2103 on the N.W. steps of the Court House at 9:00 a.m.

Watch our blog or Facebook page for further details, or contact our national office at 1-800-495-6156 or

info@dyingwithdignity.ca for further information or to confirm your attendance.

You can also join us for a pre-event sign-making session and make a sign or banner at Langara University, from 4:30 – 6:00 on Saturday March 2. We'll be in room A310.

It doesn't matter if you are a rally novice or a seasoned activist. If you believe medically-assisted dying should be an option, now is the time to show it.

P.S. Volunteers interested in helping organize the rallies should contact Galina Coffey Lewis at jglewis@telus.net or at 250-386-7772.

ASK THE EXEC.

Wanda Morris, Executive Director

One of the joys of working for DWD is the chance to speak to or correspond with our members. As a member-based organization, we're always open to your ideas and keen to respond to your questions. In this new feature, Wanda Morris, our Executive Director shares her responses to a wide range of questions that have recently come our way. Is there something you want to say? Your questions and comments are welcome too.

Q: Why is Dying With Dignity Not Intervening in the Carter Appeal?

Galina Coffey-Lewis
Victoria, BC

A: DWD wholeheartedly supports the Carter Case which featured Gloria Taylor as co-plaintiff. I provided testimony as the Executive Director of Dying With Dignity, and we encouraged our clients and their family members to do likewise. We have several reasons for not intervening though:

The first reason is simple – as witnesses for the plaintiffs, we can't intervene.

The BC Civil Liberties Association, which is spearheading the case, and I, feel that Dying With Dignity's involvement as a witness is critical. In this case, we are playing a much more important role as a witness than we would as an intervenor. We have decided to stick with that role.

We also have a further constraint as a registered charity. Only 10% of our resources can be spent on what the Canada Revenue Agency deems to be "advocacy." So we focus our efforts on education about why the laws need to be changed (which is separate from advocacy) and on key advocacy projects such as:

- media engagement,

- our new advertising campaign (see example on back page) and,
- the upcoming rally (page 3) at the court of appeal.

That said, we do not have to stay silent beyond our role as witnesses. And we don't. We see our key role as educating the public. The law will ultimately be changed by Parliament, and our primary focus is educating Canadians and their MPs.

Q. How is it that money from churches can be used to influence political decisions in a country/state where the charter separates church and state?

Joseph Gold
Manitoulin Island, ON

A. You are asking about something that is near and dear to my heart!

Yes – it seems highly unjust doesn't it? I found Marci McDonald's book, **The Armageddon Factor: The Rise of Christian Nationalism in Canada** to be an insightful, if chilling, look at how this has happened in the US and is very much becoming a model for how the religious right influences policy in Canada. The last chapter deals specifically with end-of-life choice.

In terms of specifics, the Catholic Church, like us and any charity, will be constrained to spending 10% or less of its resources on advocacy (trying to influence laws). However, 10% goes a depressingly long way when you start with massive revenue. Our primary opponent in Canada, the Euthanasia Prevention Coalition, is not a registered charity so it can spend all its resources on political or advocacy work. I believe they are funded by the Catholic Church but our financial disclosure laws in Canada are more limited than in the US, so I can't prove it. We do know that in the US, where there



"We are playing a much more important role as a witness than we would as an intervenor."

is a requirement to disclose sources of funding, millions of dollars have been spent by the Catholic Church trying to influence laws for theological reasons.

Q. Why don't you print the newsletter in colour? The newsletter would be much more attractive if it was in colour (at the least the cover and back page). You want to come across as a modern, with-it organization – colour does it.

Sheilagh Hickie
Toronto, ON

A. Many of you will have seen the on-line version and noted that it is in colour. I agree that a colour newsletter would be more eye-catching and more people would pick it up. And our fabulous content is under-appreciated if people aren't reading it. On the flip side, colour costs more. And some donors are put off by the idea of our using our tight resources to pay for "glitz."

Our print runs are growing with our membership, so the cost per newsletter is coming down. In this issue we've decided to give colour a try – on the front and back covers. Let us know what you think!

MAKING THE COMMITMENT

DUTCH TREAT

I am a paramedic. As a former long-term care worker, and growing up with a Dutch mother, I have always been interested in end-of-life choices and social justice. After reading the series on end of life choices in the Toronto Star in November 2012, I decided I wanted to be actively involved. I volunteered at Dying With Dignity.

This has been one of my most rewarding volunteer experiences: the DWD office staff is very welcoming and appreciative, and the effects of the work we do are readily visible. It is incredibly satisfying to process new memberships and donations or to send out information packages to members who wish to distribute pamphlets and newsletters in their area. I also like sending out Advanced Care Planning Kits. I have recently experienced for myself how difficult even the most basic discussion about these issues can be for some family members, and this has further convinced me of the tremendous value of planning ahead, and of open discussion about end-of-life beliefs, priorities, and wishes.

Dying is one of the most momentous personal processes, yet it's also a process over which people have the least control and fewest options. Medically assisted dying is one option that everyone should be able to consider at end of life. I think that good end of life choices start with improved education and open discussion, so I love that DWD takes such a comprehensive approach to the issue.



Leenah Walsh

A HELPING HAND FROM JAPAN

I am a nurse. While working in the Intensive Care Unit of hospitals in my native Japan, I grew concerned over the large number of patients receiving life-sustaining treatment that simply prolonged their dying, with no clear benefit. Lack of preparation for the end of life often leads to tragedy but, even when patients had a "living will," their wishes for treatment were not respected. And, once treatment is started, there is no accepted protocol for stopping it.

I came to Canada to learn about this country's more liberal and more patient-oriented medical treatment in the hope that I can help bring about change in Japanese hospitals. I am honoured that Dying With Dignity accepted my offer to do volunteer work for the organization, and appreciate that I have been given the opportunity to learn about patient rights in the different provinces of Canada by helping put together DWD's new Advance Care Planning Kits.



Marie Nuki

DWD WELCOMES STUDENT INTERN



Heather Powell is a fulltime student at George Brown College in Toronto where she is completing her Community Worker Certificate. She has been certified as a Personal Support Worker (PSW) with training from Algonquin College in Ottawa. Prior to her placement at Dying with Dignity, Heather worked in the community visiting the elderly and the sick and providing palliative support and end-of-life care for those in need in her family and the larger community.

Viewpoint:

I sought this placement at Dying with Dignity because I believe in the right of individuals to have choice when it comes to decisions about their bodies. I've personally seen too many individuals and their families suffer needlessly at the end of life. I look forward to seeing change in the right to die with dignity movement.

CARTER DECISION UNDER ATTACK

The Attorney General of Canada (AG), Rob Nicholson, has filed his appeal of the decision on the Carter Case reached by the Supreme Court of BC. The appeal will now be heard by the Appeal Court of BC in early March in Vancouver. Whoever loses the appeal court decision will seek leave to appeal to the Supreme Court of Canada.

The lengthy (62 page) appeal suggests that there were both errors in judgement and errors of fact in Justice Lynn Smith's decision for the BC Supreme Court. You can read the full appeal on our website, but here are the key elements.

Alleged Errors in Judgement

In broad terms, the AG alleges that Madam Justice Smith made a fundamental error in overturning the judgement in the Rodriguez case. He claims that any decision about legalizing physician-assisted dying belongs to Parliament and not to the courts.

The AG alleges that Justice Smith erred in accepting the possibility of harm (the inherent risks of legalization were acknowledged by witnesses on both sides). The appeal

contends that a blanket prohibition is required if there is a reasonable apprehension that harm will result from anything less than that.

The AG then alleges Justice Smith erred when applying the Charter of Human Rights and Freedoms; specifically, in finding that Section 7 (the right to life, liberty and security of the person) and Section 15 (right not to suffer discrimination) were violated.

More critically, the AG challenges Justice Smith's finding that neither of these violations can be justified under Section 1 of the Charter. In Rodriguez, Justice Sopinka, in writing for the majority, indicated that Sue Rodriguez's Section 15 Charter Rights had been violated, but that such a violation was justified under Section 1 of the Charter.

Finally, the AG alleges that Justice Smith erred in compressing the timeliness of the trial, resulting in a failure to receive all relevant testimony.

Alleged Errors in Fact

In challenging the facts as decided by Justice Smith, the AG alleges that:

The desire for a hastened death is transitory and can be addressed through palliative care and other interventions.

It is not possible to authenticate a desire for hastened death, as depression or other potential impairments must always be considered. The AG noted there are people who have been denied a hastened death and were ultimately grateful for the refusal.

There is insufficient evidence from jurisdictions that permit assisted dying to demonstrate that people with disabilities are not at risk of being assisted to die against their wishes.

There is a clear ethical distinction between physician-assisted death (sic) and other end-of-life choices. (In her decision, Madam Justice Smith noted that the bioethical community is undecided on this point.)

We await further developments with interest and will keep you posted. Make sure to sign up for our blog and email updates or "Like" us on Facebook for the latest news on the court challenge.

STAY TUNED!

Sign up on the blog page, or send us an email (info@dyingwithdignity.ca) to receive instant notices of all blog postings. Our VP John Warren does a fabulous job researching to bring you the latest information on all things related to end-of-life choice.

Recent posts include:

- International updates from Israel, France and Ireland.
- Coverage of end-of-life issues by media ranging from the Economist Magazine to Zoomer radio.
- Stories that remind us why we do this work; recent profiles include Nagui Morcos, Marica Angell and Tony Nicklinson.
- Insights from staff and volunteers (don't miss Anya's first blog – Climbing Mt Phone Greeting), and
- The latest news about the Carter Court challenge (Co-Plaintiff Gloria Taylor).



QUEBEC MAY BE JUST MONTHS AWAY FROM LEGALIZING END-OF-LIFE CHOICE

(Adapted from a blog posting by DWD ED Wanda Morris)

Last March, as part of a comprehensive report on Dying With Dignity, the all-party committee of the Quebec National Assembly issued its full report, including recommendations to allow legalized end-of-life choice for individuals suffering greatly at end-of-life.

The government then appointed three expert lawyers to a judicial panel to determine how best to implement these recommendations.

At issue is the fact that the right to medically-assisted dying is currently prohibited by the Criminal Code, which is federal legislation and thus cannot be amended by any province. However, while criminal law is set at a federal level, healthcare legislation is up to the provinces. Thus the panel recommends that Quebec introduce new healthcare legislation that will allow specific exemptions to the Criminal Code for doctors who provide medical assistance for someone to die.

Any exemption will be contingent on doctors following a strict set of guidelines to protect the weak and vulnerable.

The guidelines are very similar to those made in the Dying With Dignity Report: The Committee recommends amending legislation to recognize medical aid-in-dying as appropriate end-of-life care if the request made by the person meets the following criteria as assessed by the physician:

- The person is a Quebec resident according to the Health Insurance Act;
- The person is an adult able to consent to treatment under the law;
- The person himself requests medical aid-in-dying after making a free and informed decision;
- The person is suffering from a serious incurable disease;
- The person is in an advanced state of weakening capacities, with no chance of improvement;
- The person has constant and unbearable physical and psychological suffering that cannot be eased under conditions he deems tolerable.

The government of Quebec has repeatedly affirmed its commitment to allow medically-assisted dying by the summer of 2013. Their legislation promises to closely follow a commission report that was supported by all government parties.

They are now one giant step closer.

“Quebec was the first province to stop charging doctors for performing abortions – something they did 12 years before the legislation changed.”

Can Quebec do this? There are historical precedents. We do know that BC has already established prosecutorial guidelines that give crown attorneys discretion in bringing charges for assisting someone to end their life. And Quebec was the first province to stop charging doctors for performing abortions – something they did 12 years before the legislation finally changed. It will be interesting to see the Federal response.

CURL FOR CHOICE ROCKS AGAIN

Guelph members hosted a second successful Curl for Choice event. Our local organizers (pictured) did a fantastic job yet again. Eight teams participated, including a team of wheelchair curlers!

Curl for Choice is a fun event, a learning experience and a fundraiser. For the second year running, the teams raised more than \$6,000, and many curlers and spectators learned about the critical work of Dying With Dignity for the first time. Kudos to all who volunteered, participated and donated.



IS THE PUBLIC AHEAD OF POLITICIANS AND PHYSICIANS?

DANCING ROUND THE D-WORD

Katherine M. Svec

We live in a death-phobic culture. Death remains one of our last taboos – not to be openly discussed. Yet it affects us all.

Avoidance abounds, and the medical profession is a glaring example.

Although attitudes in the profession are not as paternalistic as they used to be, reluctance to talk about dying remains. This is particularly noticeable among specialists treating patients in late-stage medical conditions: the very conditions that demand open dialogue if the patient is to be able to make an informed decision regarding whether to accept or refuse life-sustaining treatment.

I spoke recently with Dr. Aycke Smook, President of Right To Die (Europe). I put it to him that this must be less of a problem in the Netherlands, where legalization has been in place for more than a

decade. Surely legalization resulted in more open dialogue between physician and patient, I asked? Not so, Dr. Smook tells me:

While it is true that many GPs, thoroughly familiar with both patient and family, will discuss end of life options; and while it is true that, in common with the Oregon experience, the act of patients asking for access to assisted dying will often open up discussion, this is by no means universal.

In a poll of physicians in the Netherlands by KNMG (the Royal Dutch Medical Association), around 70% of doctors admitted they were uncomfortable – and often avoided – discussing death and dying with patients.

Dr. Smook believes the answer is twofold. He says patients must know their rights and learn how to speak

to their physicians about them. Physicians must learn to listen as well as to treat.

“We live in a death-phobic culture.”

Avoidance is made easy in our youth-oriented society. We no longer grow old gracefully – we “age with attitude.” Seniors’ residences encourage us to choose them not because we are in need of care, but because they promise “we make you feel so young”. Advances in medicine have brought us the view that death can be postponed almost indefinitely.

As comedian Woody Allen famously quipped ***“It’s not that I’m afraid of my death. I just don’t want to be there when it happens.”***

GRASSROOTS FIRE

Marcie Hogan

Two strangers on Salt Spring Island each had a recurring nightmare of existing in a long term care facility unable to feed or clean themselves. Fortunately we met at a Dying With Dignity presentation by Executive Director Wanda Morris and discovered a voice for change in Canada. A door had opened, and we had a lot of learning to do.

We added the Dying With Dignity website to our Favourites, researched right-to-die societies, viewed YouTube channels and followed the Carter challenge.

We began to use the D-word with friends.

Taking courage from each other, we hesitantly spoke of medically assisted dying in living rooms, coffee shops and on the golf course. At first we were met with silence and a change of subject. However, within about 10 minutes, our friends would broach the D-word themselves and a lively discussion would ensue. We were enlightened and encouraged.

We booked a small room and invite members of our community to talk with us about a plan to expedite the change we so desired. Hesitantly,

our Seniors Centre was approached. Quietly, the name of the organization came up; “It’s for a Dying With Dignity meeting.”

“We are the face of change and the public will catch our fire.”

“I think that’s a great idea. We need you to talk to us,” the receptionist replied. “Leave some brochures. Our members want to know about end-of-life choices.”

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We wondered if we'd get more than two or three interested citizens. We were allowed the tiniest free notice in our newspaper. We were excited to find seven enthusiastic supporters, thirsty for information, passionate about their right to choose and longing to connect with others who shared their beliefs. Our local paper had sent a reporter, and we soon had an excellent article in the news. We began getting calls of support and learned our community included many long-time members of DWD.

We made plans to become a chapter. Our first presentation was Advance Care Planning. Twenty people attended that meeting, and we moved to a larger room. A donation tin helped cover our local costs. Our next meeting drew more members.

We then set up a membership table and seven more people joined on the spot. They will bring new members. Members will make death a gentle conversation among families and friends and society. Members will get brochures to curious Canadians.

We are the face of change and the public will catch our fire. Grassroots Canadians will ensure equal right to liberty and security of our person. Our generation will die with dignity!

THE DARK SIDE OF THE RISING SUN

Katherine M. Svec

The Japanese live 16 years longer than the world average. Many of the studies into this phenomenon quote genetics, healthy diet and preventative medicine.

While these are, indeed, strong contributing factors, Japan has also had a universal national health insurance system for more than 50 years, ensuring health care for all, irrespective of income. This outstanding social security system, though, does have a dark side.

“Long-term care facilities prefer feeding through a stomach tube.”

In Japan, some 600,000 patients are receiving artificial nutrition through stomach tubes, a number that has increased ten-fold in the last decade. A treatment originally designed to provide nourishment to medically fragile children is now routinely applied to patients suffering advanced dementia, the effects of major stroke or other debilitating conditions. Despite the acknowledged fact that feeding tubes are of little benefit to the terminal patient and often cause significant discomfort, no

professional guidance is in place governing conditions under which they may be removed. This applies even if the person has a “living will” stating refusal of artificial nutrition by feeding tube.

Dr. Kazuhiro Nagao, vice-president of the Japanese Society for Dying with Dignity, which is campaigning for legalization of medically assisted dying, calls this situation “the light and shade” of the universal national health insurance system in Japan, and explains three major reasons for physicians’ reluctance to discontinue this treatment.

Firstly, the medical training system in Japan is based on strict apprenticeship. Young physicians have to conform to the policy of their educators or risk losing their hospital appointment. This adherence to policy applies even if they open their own clinic.

Secondly, long-term care facilities prefer feeding through a stomach tube: it is a cheap means of feeding and the facility can't be accused of neglect. It is much quicker and easier for the caregivers, thus requiring less attendant staff.

Thirdly, it is profitable for the hospital, which receives 70% of medical expenses from insurance: (30% comes from the patients, and this is reduced to 10% for those over 65). Hospital administrators, therefore, tend to promote excessive intervention. The more treatment they provide, the higher the financial reimbursement; and under the traditional culture, patients leave most medical decisions to the physician.

In January 2012, the Japanese Geriatric Society presented guidelines for stopping artificial nutrition. The government has done nothing to ensure the guidelines are respected.

Not all politicians are unaffected by this distressing state of affairs. Nobuteru Ishihara, secretary general of Japan's Liberal Democratic Party, was sufficiently appalled during his visit to a care facility that he spoke out against this practice.

“It reminded me of the movie ‘Alien’” he said *“when I saw dozens of unconscious, bedridden people supported by feeding tubes.”*

Dying with Dignity has not yet come to Japan.

PSST! WANT A PEACEFUL DEATH?

Wanda Morris, Executive Director

If so, proceed with caution. Not all advance care planning tools are created equal.

The most popular planning tool in the US is a booklet called The Five Wishes. It was written by Jim Touhey, a Roman Catholic member of the Knights of Columbus and former Director of the White House Office of Faith-Based and Community Initiatives. Anyone using it is asked to reflect on their personal medical choices and on whether they want to be prayed over or reminded to ask for forgiveness.

While these are not everyone's top priorities at end of life, at least they are presented as a choice. Individuals are asked to strike out all that do not apply.

The Five Wishes offers minor nudging compared to the full-court press compulsion of the "Life-Protecting Power of Attorney for Personal Care" created by the Euthanasia Prevention Coalition. That document gives you no choice except to suffer...

"If I should ask for assistance to commit suicide please recognize it as either a plea for pain and symptom control management or a plea for emotional, spiritual or psychological help."

They say It's not that you are really suffering; you are just depressed and in need of a smile, a prayer or a psychiatrist.

What if that suffering becomes unbearable and your quality of life is such that you do not wish to continue? It gives you no chance to refuse nourishment; not even if you are in the terminal stages of your condition, are in Hospice, and your body is already shutting down.

"I direct that hydration and nutrition be provided to me by any means and that this be followed if I am receiving hospice/palliative care."

At Dying With Dignity Canada, we believe in end-of-life choice. We believe that only the patient can decide when suffering is unbearable, and we believe that a peaceful death at the time and in the manner of the patient's choosing is every person's right. Our Advance Care Planning Kit provides clear choices, and puts you in charge of making the decisions that are right for you.

"Not all advance care planning tools are created equal."

Make your plans now. Use our new Advance Care Planning Kit to walk through the steps you can take to articulate your wishes, to help you find ways to communicate your decisions and to show you how best to ensure your wishes for end-of-life care are respected.

Continued from page 1, JUST PRESS THIS BUTTON

Unfortunately, Ben's last days were not particularly peaceful. He thrashed about in his hospital bed, even as his caregivers steadily increased the flow of morphine. (It's now recognised among many palliative care doctors that morphine does not necessarily hasten death.) I'm not entirely certain what choice Ben would have made about the timing of his death. But, having witnessed his last days and hours, it's hard to imagine he would have chosen the death he had.

Looking back almost two decades, I am surprised that I'm now older than Ben was when he died. Today, I am also a Unitarian Universalist minister. So much of what has shaped my understanding of ministry – indeed, so much of what has formed my understanding of the precious and precarious gift of life – I learned from

caring for Ben. And so much of what has inspired me to advocate for greater choice in the way our lives end is rooted in bearing painful witness to Ben's death.

"Having witnessed his last days and hours, it's hard to imagine he would have chosen the death he had."

There in that hospital room, his doctor and I had a veiled conversation that would never have been necessary had Ben had the legal right to decide to end his life with dignity and peace. I pray every day that this may be a right we all someday share.

IRISH COURT DECISION SAD, AND SADLY NOT UNEXPECTED

Condensed From an Article in the Irish Times

Marie Fleming lost.

Marie is a severely disabled woman in the final stages of multiple sclerosis. She asked the Irish High Court for the right to be assisted to die so she could avoid her fears of a “horrible” death during which she could not communicate .

Despite the fact that other jurisdictions have provided safeguards that peer reviewed studies have indicated are working, the three-member panel ruled it would be impossible to provide safeguards that ensure the weak and vulnerable never used the legislation simply to avoid being a burden on their family or society.

The weak and vulnerable in this case were further described as “the aged, the disabled, the poor, the unwanted, the rejected, the lonely, the impulsive, the financially compromised and the emotionally vulnerable.”

The court case also asked the Director of Public Prosecutions (DPP) to set out the facts to consider in deciding whether to prosecute cases of assisted suicide(sic). The panel ruled that providing such guidance would be unconstitutional as it would result in the law not being enforced. The court noted that if an assisted suicide (sic) were to occur, the DPP would review the

evidence and would exercise her discretion “in this of all cases” in a “humane and sensitive fashion.”

High Court President Mr. Justice Nicholas Kearns did note that Ms. Fleming was “in many ways the most remarkable witness” and also that “her courage in adversity is both humbling and inspiring.” He added that, if the court could tailor-make a solution just for her, a great deal might be said for her case.

The court did agree to award costs to Ms. Fleming and noted that it believed the Director of Public Prosecutions would exercise discretion in all cases in a “humane and sensitive fashion”.

DWD Response: The Logical Flaws in the Irish Case

Those who oppose end of life choice argue that a “blanket prohibition” is required otherwise someone, somewhere will come to harm.

To live is to risk: the activities that create risks can also greatly enhance our lives. We have clearly established the right to assume risks when the alternative is to infringe upon personal autonomy. Patients are ultimately responsible for deciding their medical care. Healthcare professionals can recommend, but never require, particular treatments.

We already have laws and safeguards in place to allow individuals to exercise their right to be taken off life-support or cease life-sustaining medications. The

same safeguards would be in place for requests for medical aid-in-dying. Currently, where doctors or other medical professionals have reservations about the underlying reasons for an individual’s decision, for example, if they suspect a request is motivated simply by age, disability, financial circumstances, loneliness, or emotional vulnerability then further assessments by trained professionals are required.

By striving to completely eliminate risk in this case, we ignore the tremendous suffering of those who are harmed by this prohibition.

The court’s comments that “should someone be assisted to die, in a case such as this, the Director of

Public Prosecutions would exercise discretion in a humane and sensitive fashion”, is little short of bizarre. Essentially, they say, we pity you and we think you deserve this right but we can’t give this to you without allowing others to have it. And if we gave it to everyone, some idiot somewhere will do something stupid. Nor can we authorize guidelines for you to have it. That’s not on. However, if you do go ahead, say, by using guidelines established elsewhere, well, the DPP is a good sort and we’re sure she’ll do the right thing. Right.

I’m guessing that Marie Fleming and her partner, John Curran, are not tremendously reassured.



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@DWDCanada



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facebook.com/DWDCanada

2012 AT A GLANCE

On Track for Financial Sustainability

We have once again exceeded our budget for revenues and anticipate being at break-even or better for the year, according to preliminary financial results (subject to audit) for 2012. This continues the positive trend started in 2011 and puts us on solid financial footing for long-term sustainability. Membership growth continues to drive up revenues (graph 1).

As part of our commitment to transparency, we will post our audited financial statements on our web site as soon as they are available. The budget for 2012 will be presented at the AGM in May 2013. Interested members can also request an advance copy from our national office.

Social Media Impact Increasing

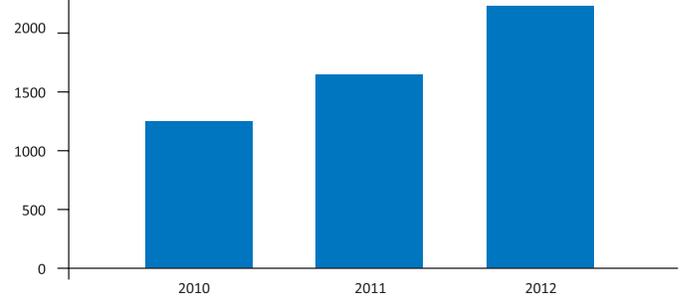
We've also strengthened our voice on social media and through the increased reach of our website. Our "Likes" on Facebook indicate rapidly growing support from members and non-members alike (graph 2).

Client Support Experiencing Exponential Growth

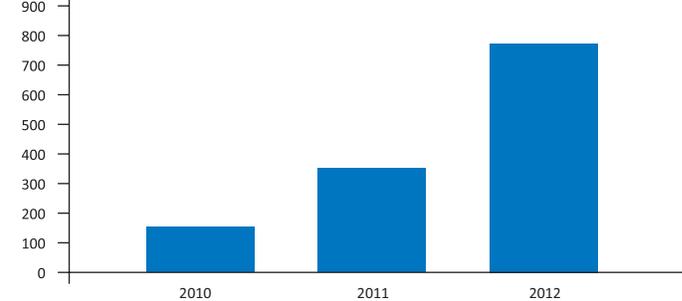
Recent publicity about Nagui Morcos and other DWD work has dramatically increased public awareness of our Client Support Program. The number of members we supported more than doubled over the past year (graph 3).

Thank you for your continued support – and watch out 2013!

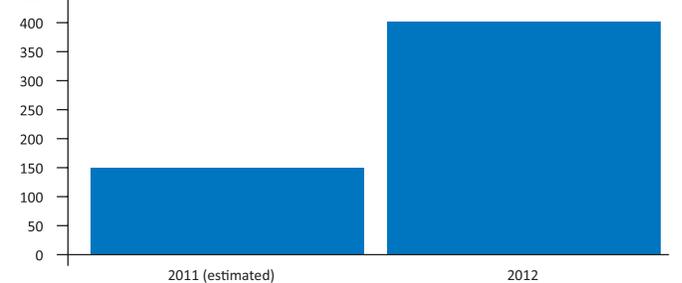
DWD Members and Supporters as of December 31



Facebook "Likes" as of December 31

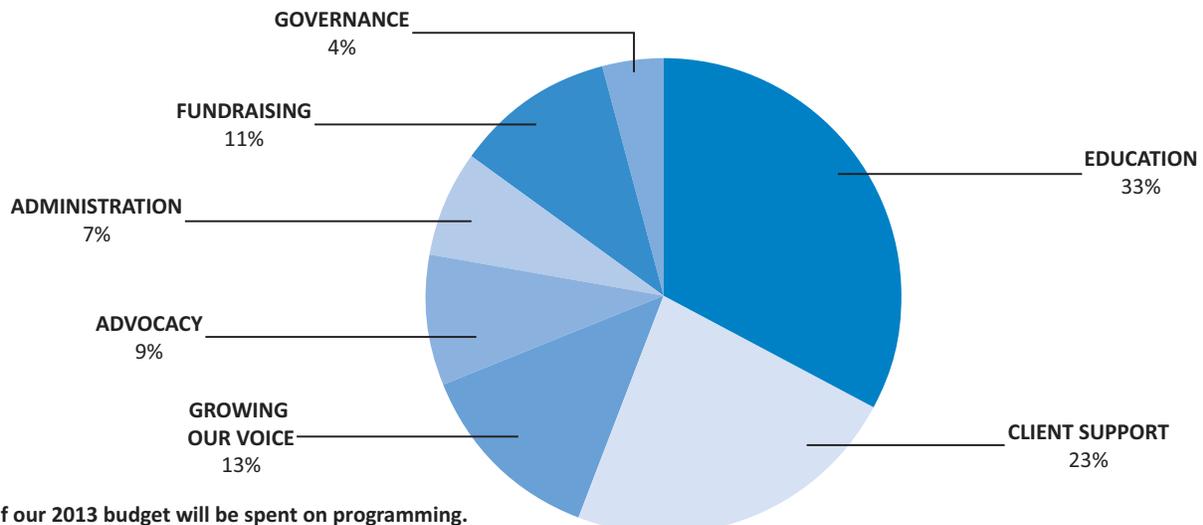


DWD Members Accessing Client Support

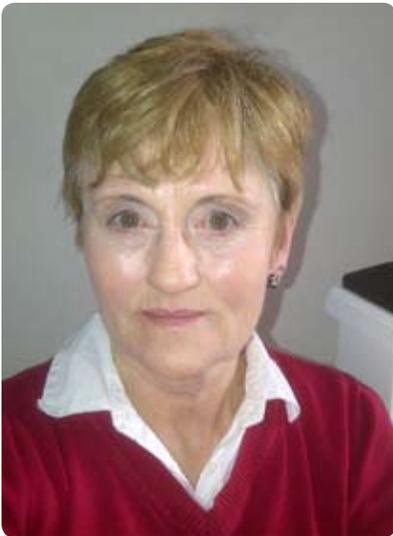


BUDGETED EXPENSES FOR 2013

Our Board has now approved our 2013 operating and capital budgets. A breakdown of our budgeted spending by category is shown below. Members who are interested in receiving our detail budgets should contact Anya Colangelo for a copy. The budget will also be presented at our AGM.



DWD STRENGTHENS BOARD WITH TWO NEW MEMBERS



Maxine Cupido, MSW

Maxine has spent her life working in health care, initially as a Registered Nurse, then as a Social Worker. She has extensive experience in working with the elderly and their caregivers in hospital and community settings. She also brings five years of experience as a Capacity Assessor to her board role.

Viewpoint:

While medication and palliative care can make many patients more comfortable at the end of life, the current system inflicts great discomfort and indignity in death on some. This is unacceptable for the patient and gruelling for family members and caregivers. I am very concerned with the position many professionals and family members find themselves in when a patient or loved one has asked for help in dying. We can refuse to address the patient's wishes and just watch the person suffer, or we can 'go underground' and put ourselves at risk of prosecution. It is time for us to have an adult conversation about end of life choice, including changes to the current law to protect those who are put in such an impossible situation.

Gregory Robinson, MD MHSc CCFP FCFP FRCPC

Greg is a retired physician with a specialty in Public Health Sciences. For many years he delivered family-based care in a palliative care setting. He also has a background in clinical epidemiology and a history of advocating for disability and rehabilitation issues. Greg was the inaugural recipient of the Award of Excellence in HIV and Rehabilitation. As an individual living with a terminal diagnosis, Greg also brings a personal perspective to the work of dying with Dignity.

Viewpoint

Everyone deserves to die with dignity. We now need to extend our compassion and allow each individual all possible choices to end their life in peace.



IT'S NOT ALL SPAM!

Lisa Gosselin, DWD IT Volunteer

In 1978, one spam e-mail was sent. The debut spam advertised a computer company. It annoyed 400 people.

In 2012, spam accounted for 73 per cent of all e-mail traffic. It annoyed everybody.

Attempts to fight the overload account for plenty of lost emails and miscommunication. DWD is hearing that some of our emails are being lost, and we suspect they are in spam folders. This seems to be a particular problem for anyone using Shaw as their Internet provider. As we work with our service providers to improve email deliverability, we need your help to confirm your settings.

You can find instructions for Hotmail, Gmail, Shaw and Yahoo email accounts on our website in the resources section "It's Not Spam". If you are using an alternate email provider and are not receiving DWD emails, please contact me at lisa@dyingwithdignity.ca



FILM REVIEW

TERRY PRATCHETT: CHOOSING TO DIE

By Dianne L. Woodruff, DWD volunteer

Terry Pratchett's award-winning BBC documentary (2011) is a sensitive exploration of medically-assisted dying – not by politicians or doctors, but by those in need of it. Pratchett, diagnosed with early-stage Alzheimer's, interviews other Brits with terminal neurodegenerative illnesses. Their heartfelt discussions directly address the need for end-of-life assistance, which is unavailable in the UK.

The film features Peter Smedley who, at 71, suffers from motor neurone disease and is approaching a critical stage. If he is to hasten his death, he must physically take the prescription by himself. He and his wife travel to Switzerland where Dignitas grants him the help he needs with sensitivity and compassion. The documentary also gives the viewer an inside look at Dignitas, its volunteers and its quiet ambience.

The BBC was criticized for this documentary that, without taking a position, makes a valuable contribution to the debate on who determines when and how we die.

OUR NEW AD CAMPAIGN

We are extremely excited about the ad campaign (see example on back cover) created for us by Peter Jennings, a Muskoka-based marketing executive and university guest lecturer, who has volunteered his time and expertise.

Many publishers provide free ad space to charitable groups as a community service. They are often seeking high-quality, print-ready ads just like the ones Peter Jennings created for us. Please download your favourite from the resources section of our website and send it along with a cover letter (see a sample in the resources section) to community and local newspapers where you live. Or download and print an add and post it on a public or community bulletin board.

Don't have computer or printer access? Just give us a call and we'll happily send you some ads to post in your community.

KATHERINE'S CORNER – BE YOURS TO HOLD IT HIGH

Katherine M. Svec



Dr. Peter Goodwin, who was instrumental in helping pass the Oregon Death With Dignity Act, and was a moving force behind our sister organization Compassion and Choices, died last year. When he received the news that his condition was terminal, he made the decision to take advantage of his rights under the law he had helped pass.

On Sunday, 11th March 2012, Dr. Goodwin died as he had planned – surrounded by his family. One of the many moving messages he left us was an exhortation to continue the struggle in which he had been so deeply involved.

“To you from failing hands we throw the torch; be yours to hold it high.”

This inspiring quote comes from the poem “In Flanders Field” written in World War I by Canadian physician Lt. Col. John McCrae. The poem is often included as part of Remembrance Day services.

*Take up our quarrel with the foe:
To you from failing hands we throw
The torch; be yours to hold it high.
If ye break faith with us who die
We shall not sleep....*

Nagui Marcos, DWD volunteer and spokesperson, was a tireless advocate for end-of-life choice but did not live to see it become a reality in Canada.

Increasingly incapacitated from Huntington's disease, Nagui ended his life on Sunday 22nd April 2012, as he had planned, and while he was still able to do so unassisted. In his final letter he makes a plea for the legalization of medically-assisted dying in Canada.

I now pass the torch to you, my dearest family and friends, to do the right thing and change this (law) so that you and your loved ones will have more choice than I did.

These two brave men have left us a legacy of courage and commitment, and have charged us with a mission: to continue their struggle to throw light upon a dark corner of our legal system.

MEMBERSHIP



Dying With Dignity
It's your life. It's your choice.

Count me in! I want to join Dying With Dignity!

- \$50 Individual \$20 Students \$75 Family
- \$100 Organization \$750 Lifetime Individual
- \$_____ Pay What You Can – Compassionate Membership

I would like to make a **special one-time donation** of:

- \$500 \$250 \$50 \$_____ My Choice

Other Resources (Please send me the following)

- Advance Care Planning Kit (free with membership or equivalent donation)
- eBulletin (free, please provide email address below)
- Other: _____

- Mr. Ms. Mrs. Dr. Other _____

Name

Address

City

Province

Postal Code

Email

Phone

How did you hear about Dying With Dignity: _____

For recognition purposes:

- Please display my name as: _____
- I prefer to remain anonymous

Payment Information

Total Payment: _____ Cheque (payable to Dying With Dignity) VISA MasterCard

Credit Card Number

Expiry Date

Name on Credit Card

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Return to Dying With Dignity via mail, fax or email for immediate processing. REGISTERED CHARITY 11889 0086 RR0001

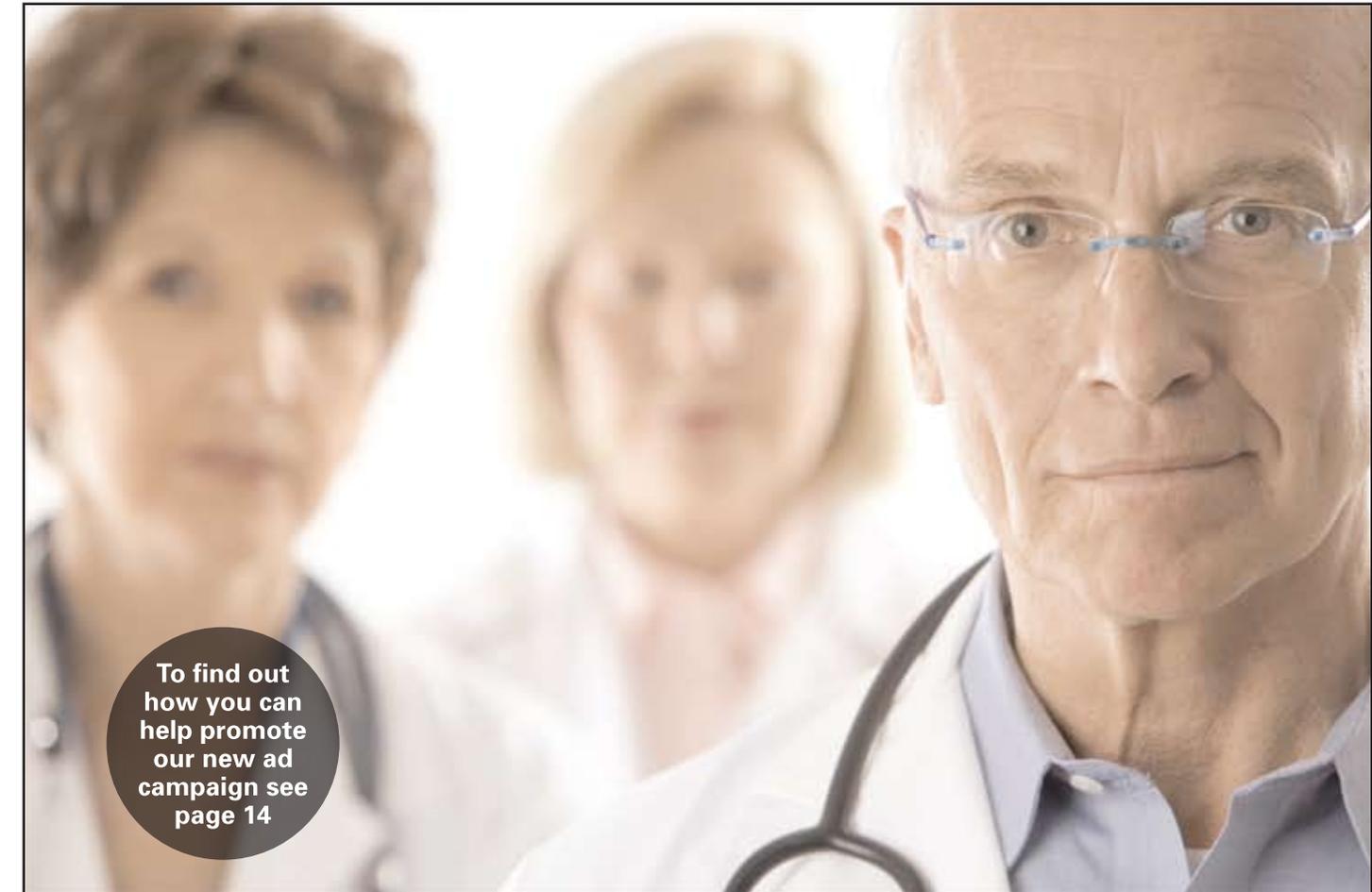
Be a leader for choice!
Join our Giving Circles*

- \$250 - \$499
Circle of Support
- \$500 - \$999
Circle of Hope
- \$1,000 - \$2,499
Circle of Compassion
- \$2,500 - \$4,999
Circle of Choice
- \$5000 and over
Circle of Justice

*Giving Circle Membership is determined by total annual donations.

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Email: info@dyingwithdignity.ca
www.dyingwithdignity.ca



To find out
how you can
help promote
our new ad
campaign see
page 14

An Advance Care Plan ensures I understand your wishes.

Members of the medical profession are tired of inflicting unnecessary suffering on patients facing pain at the end of their lives. But without an Advance Care Plan or a Do Not Resuscitate Order, they are often handcuffed into carrying out procedures that will only prolong the patient's trauma.

Dying With Dignity is the national charity that comforts Canadians by offering emotional support and information on legal end-of-life options. Our goal is to end unnecessary suffering while providing peace of mind and confidence to those

seeking clarification on their choices. We also discredit myths about the dangers of legalizing medically-assisted dying.

We offer advice on how to complete an Advance Care Plan and provide free resource kits to our members to help ensure their wishes for end-of-life treatments are followed.

We invite you to visit www.dyingwithdignity.ca where you can learn more about your rights and options and become a member of the charity that puts your needs first.



Dying With Dignity
It's your life. It's your choice.

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