

To Be Or Not To Be?

Two Women With Disabilities

by Tanis Doe and

Débatte le droit de mourir lorsqu'il s'agit de la vie de quelqu'un d'autre ou lorsqu'il ne s'agit pas d'une personne en particulier revêt un aspect très existentiel. Cependant, la question «Être ou ne pas être» prend une nouvelle dimension lorsque c'est de votre situation qu'il s'agit. Cet article, sous forme de discussion entre les deux auteures, discute du droit à l'euthanasie.

Women with disabilities have been assaulted not only by individuals in their lives but also by a legal system and mass media that claims authority over their physical bodies as well as their minds. Women with disabilities of all types have had their bodies measured, altered, and judged by medical professionals, policy makers, and the general public. The question of whether to live or die must come back to the individual woman with a disability. The following dialogue is one that does not only take place in faculty rooms or at conferences, but also in living rooms, bedrooms, and sometimes hospitals. To be or not to be. Whose choice is it anyway?

Tanis

I wanted to die. I know I wanted to die. I wanted life to end as much as I wanted suffering to stop. I was not terminally ill. I was not even severely disabled in a medical sense. I was chronically ill and felt that my own depression was worse than any possible disease or disability. But I am alive to talk about it and glad that I am alive. I can honestly say that I am happy to have survived depression and that others like me are still alive. Some of us were rescued by friends or crisis lines and others just didn't succeed at getting dead. But we are only one side of the story. How can we ask the women who were actually able to die? Why do we assume that all the women who failed at suicide are the successful ones?

I do not want to debate the afterlife or the ethics of dying. I want women to enjoy living, and to participate in a satisfying life, but I also want to ensure that suicide is a choice for us.

For me it was actually both. I did ask for help, and [I did] get some help before I tried. I attempted suicide by over-dosing on medication given to me by a doctor, combined with alcohol.

I remember waking up thinking I was once again a failure and couldn't even kill myself properly, but that seems to be common. It is actually difficult to know how to die safely. By "safely," I mean finding a way that will end your life rather than result in permanent brain damage or further disability. Women tend to attempt suicide more often than men, although men are more likely to actually die during their attempts. I think many women are medically treated or restricted during their expression of suicidal thoughts, which makes it very difficult for them to complete their wishes.

Barbara

You say you wanted to die because you were chronically ill and depressed; I can relate to your situation because twenty years ago I was depressed and deeply dissatisfied with myself as a mother shortly after my daughter was born—it was probably tied in with post-partum depression. I remember how real my feeling was that everybody including my daughter would be better off if I was dead. But I'm glad I didn't "succeed." My failure at suicide felt like a "success" because afterwards I saw my attempt as a cry for help which I couldn't overtly articulate at the time. Fortunately, I did receive counselling which helped me build up the self-esteem and confidence that I needed in order to regard my life as worthwhile and fulfilling. Since then, whenever I contemplate others' failed or successful suicide attempts, I think of them as desperate cries for help, and thus if the woman fails at suicide I do think of her situation as more positive or successful than if she dies. I do think there is a reality that there are many people who killed themselves who could have gone on to live out their natural lives if their suicide had failed and intervention had taken place. I do think of people who are in a suicidal frame of mind as being emotionally disabled. In your case, did you actually attempt suicide or did you seek help beforehand?

You make an interesting point in saying that women are more medically treated or restricted, and thus less successful in their suicide attempts. The two most famous cases in the Canadian "right-to-die" movement were initiated by women with disabilities, Nancy B and Sue Rodriguez. I don't think either of them thought of their legal battles as gender-based. However, if we acknowledge that women in general and women with disabilities in particular tend to have less control over their lives than their

Whose Question Is It, Anyway?

Discuss the Right To Assisted Suicide

Barbara Ladouceur

I feel very strongly about the right to commit suicide because I know that it was a choice for me. When I hear that for some people it is not a choice because of disability, it scares me. Women with disabilities are not able to make their choices because society legally takes away their rights. Does this mean that as women, we are devalued by society, labelled by medical professionals and marginalized from the mainstream, and yet refused this final dignity of choice? They try very hard to prevent fetuses with disabilities from being born, yet once we are alive they won't let us take our own lives?

It has a rather paradoxical ring to it: we don't really want you here but we won't let you leave either. And this is important because there are many ways to address the issue of wanting to die.

If everyone wanted us to be part of society, if all access questions were already dealt with, and perhaps integration was commonplace, would some women with disabilities still want to die? Yes.

We still might want to die the same way thousands of non-disabled women want to die, and their situations are often very different from the lives of women with disabilities. The complexity and diversity of motivations must be considered because disability is not the only "justifiable reason" for wanting to die.

Should it matter if you want to die because of Alzheimer's or because of a personal crisis? In fact, it is silly that if someone is not fatally ill but physically able enough to end her own life we allow this, but if the person is so ill or incapacitated that she requires assistance, then we don't allow it.

Intervention that might be drugs? Or maybe electroshock therapy or restraints and isolation? It is difficult to condemn women's choices when their alternatives seem so poor. So there are two questions about women with disabilities choosing death that need to be thought through—one is their motivation and the other is their ability to follow through with their ideas.

male counterparts, it does seem most appropriate that it is women leading the fight for the ultimate choice: to be or not to be.

I agree with you that women with disabilities are especially devalued and marginalized by mainstream society, including the health care professionals to whom they go for service. When you point to the issue of choice, it seems to come down to the ongoing issue of women's control over their bodies, again.

I see parallels with the abortion issue—anti-abortion groups wish to deny all women the choice to terminate pregnancy, yet they do not on the other hand support every child's welfare after birth. There are not large-scale efforts by society in general to show that we value the lives of all children, or to alleviate their problems.

So the message seems to be that all children are valued until they are born, when they have to contend with mainstream society's hierarchy of rights and privileges. Children are certainly not born equal when there is still such deeply entrenched sexism, classism, racism, and ablism in society.

You are saying that we should separate the issue of disability as the motivation for a women committing suicide. We are getting into another paradox because the right-to-die movement is based on the person having a "justifiable reason" for ending their life. It is argued that if a person is terminally ill and/or permanently and severely disabled, they have the right to end their lives because their suffering has become unbearable or the quality of their lives is non-existent. Women with disabilities understandably feel devalued when the degree of physical disability is put forward as justification for suicide. When I follow your line of thinking to put aside motivation and focus solely on the concept of every person having the right to decide when and how they will die, I feel comfortable in saying that I agree with this idea. If a woman kills herself then she has successfully exercised this right. But I am still haunted by the possibility that she was in a temporary state of mind—suffering an emotional disability that could have been alleviated by intervention.

You are so right. Given the reality of women's lack of self-esteem and/or lack of "success" in life being rooted in concrete prescribed codes of behaviour according to gender which already

Motivation for death is not always due to one specific issue. Some older women want to die to avoid wasting away or suffering unnecessary and intrusive medical procedures. Some people feel that pain is unbearable and prefer the shelter of death over drugs to resolve their pain. Other women may want to die because life has become so emotionally and spiritually empty that life is of no value. The discussion about suicide usually ends up with the issue of disability not being considered worth dying over. In fact, it is not always their disability that motivates women to want to die. In any event, the reasons women choose to die should not affect the judgement of others in power.

The second issue is being able to carry through wishes. Searching out and being able to administer a method of death is problematic for women with disabilities. Often the difficulty is finding one that is fatal enough that one can be sure of death and not another version of existence which could possibly be worse than the current situation. But women with severe physical disabilities who need assistance with daily chores and personal care may be dependent on others for several types of assistance. In fact it is the issue of assistance that is almost more contentious than that of choice. Once a woman with a disability who is dependent on others has made the choice to die, who will help her? Can she ask her friends or doctors to do this? If she asks and they refuse, what action can she take? It seems almost cruel to deny a person who normally receives assistance without question this final assistance. Can I have a glass of water please? Can you move my left arm onto my lap? If an assistant ignored these requests and continually denied the woman food or comfort it would be criminal. In fact, it would be considered abuse and neglect if it continued.

But women with disabilities who are asking not to be fed, or not to be connected to machines or even to be given medication that would result in death, are not being helped. The helpers themselves are not necessarily making these judgements. There are countless situations that have never been publicized in the media in which women had their friends help them make the final exit without much attention. However, once the public sphere is involved, once there are media, courts, and politicians, death no longer becomes a choice. Death becomes a legal debate, an ethical question, and a political issue.

In many cases women with disabilities have had their rights taken away by the medical system which labels them as incompetent. An insidious legal technique is to institutionalize and medicate her, this process also dehumanizes the woman. Judges look favourably on a medical doctor's opinion regarding the mental competency of a patient, particularly suicidal ones.

In fact, even a layperson would agree that no one in their right mind would want to die. Ergo, suicidal women are mentally incompetent, with legal and medical procedures to support this. But the politicians have a hand in this too.

restrict their life choices, how can others tell us that we are mentally incompetent if we want to die? Perhaps the opposite is true.

When I contemplate the overwhelming problems of our world—hunger, war, environmental devastation—and when I visualize the huge number of people, especially women and children, trapped in oppressive and violent situations, it seems clear that a right-minded person would certainly be justified in wanting to make a final exit. I would still prefer to achieve more options and control over our lives for all women, so that less lives are “emotionally and spiritually empty,” but such a revolution is not likely to be achieved in the near future.

The right to die is such a complex issue, I have conflicting ideas within me. Yes, I can agree that all women should have total control over their lives including whether to end them but if it was my daughter or friend who successfully committed suicide, I'd be devastated and definitely regret that I hadn't been able to intervene. I guess you could say that sometimes the political conflicts with the personal. So let's move on to the second issue.

Yes, it may be that relatives of caregivers are just not emotionally or morally capable of enabling a woman with a disability to end her life. Perhaps our society will have to support more doctors like Kavorkien who are physically and emotionally removed from such situations. They are perhaps in a better position to “objectively” and non-exploitably agree to assist people to die. If we put aside the potential for exploitation and the issue of motivation in order to morally and legally recognize the right to die, then maybe we need “death doctors” just as there are abortion doctors and still others who won't participate.

Otherwise we run into another tragic paradox. I can agree with a woman's right to choose death, but I also think whoever is requested to assist her death has the right to say no for whatever moral or emotional reasons they may have. Following this logic, it is unfortunately quite possible that although women with disabilities may have the legal right to die, there will be no one in her life who can or will assist her to die. Because no one should be forced to help someone die, we are possibly moving towards the ultimate conflict of interests.

I like your point that it is only when the issue of suicide becomes public that choice is eliminated and suddenly strangers are given the right to tell us whether or not we can choose to die. But I do think it is more a question of the final and irreversible consequences of assisted suicide rather than the apparent inequality of rights we see when we acknowledge the ability of an able-bodied woman to kill herself versus the inability of a woman with a disability to kill herself due to lack of assistance. If a person assists a suicide, then they may wonder if the suicidal person might have later changed their minds about wanting to die. They may question themselves as to whether they made a correct assessment as to whether the assisted suicide was actually in the suicidal person's best interests. In any other “helping” situation, you can still see and communicate with the assisted person and evaluate how they are doing in order to adjust or change strategies accordingly.

Suicide has been decriminalized as an act, and yet assisting or encouraging suicide is still against the law. It seems quite discriminatory that this law about suicide was made by able-bodied people who would be able to take their own lives without assistance if need be. However, if a woman with a disability makes the choice to die on her own, and needs help to carry it out, is she a criminal? More specifically is her assistant a criminal? The injustice is obvious: there are two types of equality—equality for those who are able-bodied, and equality for those who are different. Women are already subject to many kinds of violence and control over their bodies. Women are raped, assaulted, battered, stalked, and robbed by people who have power over them. Suicide is a way for woman to have control over their own lives.

The question of abortion, of fetal testing, or genetic manipulation is not being debated in this case. It is adult women, not science that is being discussed. Some women have become disabled, and generally feel it is tragic that their lives have changed. Some women have had disabilities throughout their lives and continue to lead happy productive lives. Regardless of their status in life, all women must have death as an option. Not because society wants them to die, but because it is a legal and moral obligation of society to allow the dignity and security of the person. Choice.

Choosing death over life is not a decision made hastily. In fact, there are probably many women who have regretted attempted suicides and are now leading fulfilling lives after treatment or life situation changes. But there will always be women who do want to die and do need help in order to kill themselves. If you are so physically dependent on others for assistance that you need to ask to eat, then you should also have the right to not eat. Forced tube feedings and intrusive operations against personal wishes seem far more criminal than the issue of assisting a choice of a woman.

Questions are raised about abuse, or rather overuse of this process should it be legalized. Too many people would “help” others die, and there would be ulterior motives in assisting suicides, issues of living wills, estate, inheritance, and burden would come up. There are equally large numbers of violent crimes that now occur, particularly against women, which are not being adequately addressed by the existing laws. In fact, there may eventually be a long list of situations which allow for assistances and others which preclude it. Yet this again avoids the question of choice.

Lawyers and medical professionals are paid well for their work but women with disabilities, for the most part, are poor, and they are not able to spend their last dollars on hiring specialists to defend or evaluate them, and often would be unwilling to use their time and money for this. The issue of choice must be a personal one, and that choice should be legalized so that no procedures are initiated once the choice is made.

The trouble that some disabled women have with this issue relates to quality of life. Women with disabilities suffer higher

At an abstract level, I agree with the right-to-die concept, but when I visualize concrete situations, I start having doubts because once the person has died, they can't come back and assure you that the right decision was made. It's one thing to decriminalize suicide when a person commits the act on their own, but when other people become involved, the issue becomes much more complicated with a wider range of circumstances and variables to be assessed.

Yes, women with disabilities must have the right to refuse care or treatment. However, the ending of life-support efforts does appear more feasible in terms of merely requiring the cessation of intervention by health-care professionals. But actually *taking* action to kill a person, even when the person has requested death is more problematic. There is always the legitimate concern that caregivers who are already powerful forces in the lives of women with disabilities could exploit a woman's right to die in the interests of the caregiver and not the woman. So I can only agree that on the one hand women with disabilities must have their choice to die respected and, if necessary, assisted, but as long as society builds in safeguards to assure that the woman with a disability herself has decided to die and that no one coerced them into their decision in order to exploit her.

Just as outside parties such as police, lawyers, and judges often have to enter an abused woman's life situation in order to assess the appropriate action to protect her against her abuser (such as issuing a restraint order) which guarantees her right to life, so too there should be outside parties involved in the process of facilitating a woman's right to die and to assure that it is in her *own* best interests and not someone else's.

Women with disabilities are not supported in their choices to die, to live or to procreate, because a system of legal and medical procedures is in place to make decisions for women. But non-disabled women, and to an even greater degree, able-bodied men, are given better choices because of the lack of restraints in their lives. If they choose to die, it is a private matter and their decision. Women with disabilities lack this freedom of choice in death.

Remember that women with disabilities are not asking *only* for the right to die. Women with disabilities want to live, and live happily and with positive results, but they cannot do that without control over their bodies. It does come back to the role of women's bodies in society. Women in general are seen as baby-makers, life givers, and service providers. But women with disabilities challenge that role and confuse the everyday assumptions about the role of women. As a result, there are endless possibilities for debate: Can women with disabilities reproduce normal healthy babies and do we want these women to be mothers? Should we allow a fetus with an obvious disability to be brought to term? Which disabilities are considered severe enough to terminate pregnancy and which disabilities in adult women should preclude her from being allowed to have children? Can a child or woman with a disability experience any quality of life beyond that of mere existence? If she wants to die should we let her? Should we help her? Who are we to decide for her, whether she is to be or not to be? Whose question is it anyway?

rates of sexual and physical abuse, live with psychological abuse, and generally are mistreated by society. Some women with disabilities advocate for better education, safety, and employment while others work for better personal assistance, transportation, and housing. Regardless of the status of women with disabilities in general, a woman with a disability can personally make a choice to die. The issue of birth and death is also tied in with the issue of choice—thousands of women have taken their own lives because of inaccessible abortions. Thousands of women have died because of illegal and unsafe abortions. Choice is a matter of life and death for all women. But even if the situation for all women with disabilities was horrible and painful, each woman would still have to make the personal choice. There is no general rule or procedure because it is a matter of choice. If everything in this complicated world was perfect and accessible to women with all disabilities, some women as individuals would still need the right to make the choice to live or die. It is my life, and my choice to make.

Tanis Doe is a deaf advocate (with other disabilities) who works independently and in collaboration with organizations and other researchers to effect social change. Tanis has an adopted deaf daughter who is now eleven years old.

Barb Ladouceur has an M.A. in Women's Studies and is a feminist writer working in the areas of women and poverty and women and disability. She particularly believes in the educational value of publishing women's stories. She has a hearing impairment and has been a single parent of two children for several years.

**DAWN Canada
Suicide and Abuse in the Lives of Women
With Disabilities**

Although DAWN Canada has been working for five years toward making support services accessible to women who are victims of violence, it is still very difficult for a woman to access those services, especially when she is depressed to the point of being suicidal.

DAWN Canada is committed to helping women with disabilities who are feeling suicidal. We are presently doing a survey of women with disabilities on Suicide and Abuse. We want to determine why women are feeling suicidal and whether or not it is linked to abuse in their lives. We also want to know what they feel would be the biggest help to them in overcoming these feelings. We are mailing questionnaires to women with disabilities across Canada asking them to participate in this survey. We are also doing a survey of the accessibility of crisis counselling centres. Our goal is to make counselling services more accessible to women with disabilities. If any woman with a disability is interested in participating in the survey please contact Shirley Masuda at (604) 273-7239 to receive a copy of the questionnaire, or for an interview by phone or in person.

Shirley Masuda is Senior Researcher on issues of violence against women with disabilities for DAWN Canada: DisAbled Women's Network Canada.

KATHY FRETWELL

Marilyn

Your magazine photo lingers:
checked shirt & denims,
brown-haired Norma Jean at home,
a dream

The negative is
that superimposed MM
shaped like a cleavage,
an ass

Lee Strasburg
blessed your acting
The Hollywood machine
cemented you, a star
walked on by every
restless sole

I dreamt me
as you,
Marilyn: scarlet lips
ammonia-blonde waves,
the pencilled beauty mark,
and chanted to my sisters:

I'm really Norma Jean
Moguls pulled the strings
in my valley of the dolls
Madonna sang about
my drugged seed
I arched to flower
but semen slicked me down

I/con for males,
wombdeep I tunnelled anger,
thrust under the president's men,
hoping to bear
fruit in my field

call me unwilling martyr,
bad example,
still I visit
your dreams

Marilyn, you spook us
to be natural

Kathy Fretwell lives in Parry Sound, Ontario. She has had poetry published in magazines and journals across Canada and the United States.