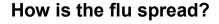
# **ACCESS Health**

# Influenza (Seasonal Flu) and the Influenza Vaccine

http://www.toronto.ca/health/cdc/factsheets/pdf/fs influenz a.pdf

nfluenza (the flu), is a virus that comes around each fall (making it seasonal) that causes fever, chills, muscle aches, headache, runny nose, cough, weakness and tiredness. These symptoms usually last two to seven days. The cough and weakness may last for up to six weeks. Elderly persons may have the flu without a fever, and children may have stomach symptoms such as nausea, vomiting and diarrhea.

Who is at risk? Everyone is at risk of getting the flu. Although most people will not get seriously ill, some people may develop flu-related complications such as lung infections (pneumonia), ear infections, dehydration (loss of body fluids) and, in rare cases, death. People most at risk include: children less than two years of age; people 65 years of age and older; residents of long-term care homes or chronic-care facilities; people with chronic health conditions such as diabetes, cancer, lung, heart or kidney disease; pregnant women; aboriginal peoples; and people who are obese.



You can get the flu if you are coughed or sneezed on by someone who has the flu. Touching hands, surfaces or objects that someone with the flu has touched and then touching your eyes, nose or mouth can all lead to getting the flu.



Volume Two Issue Three

Fall 2011

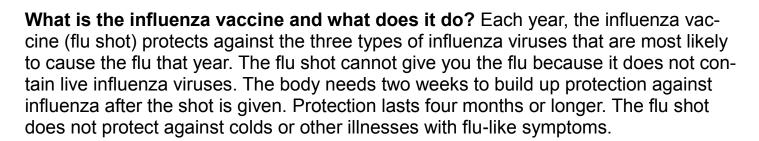
Inside this issue:				
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#### What can I do to prevent the spread of the flu? Get the flu shot each fall.

Also follow these simple steps to protect yourself:

- wash your hands frequently
- cover your cough and sneeze with something other than your hands
- stay home when you are sick
- drink plenty of fluids
- be physically active
- avoid touching your eyes, nose and mouth with unclean hands
- avoid close contact with persons who are sick with the flu
- stay well rested
- eat nutritious food



When should I get the flu shot? As the flu shot takes two weeks to provide full protection, the earlier you get the vaccine the better. The flu shot is available starting in October.

I got a flu shot last year. Do I have to get it again this year? Yes. You should get the flu shot each fall. The viruses that cause the flu change frequently. Protection from last year's vaccine has likely worn off. You need to get another shot to be protected this year.

Who should get the influenza vaccine? Everyone who is six months of age or older should get the flu shot, unless there is a medical reason that prevents you from getting the vaccine. If you are at high risk for flu-related complications or live or work with people who are at high risk (e.g. healthcare workers and essential community services staff), getting the flu shot is particularly important.



How many doses of the vaccine do I need? Adults should receive one shot each year. Children between six months and eight years of age who never had a seasonal flu shot should receive two doses the first year they get vaccinated. These two doses should be received at least one month apart, and they need one shot each year after that.

What are the side effects of the flu shot? The flu shot is very safe. The most common side effects are soreness or redness where the shot is given, fever, headache or tiredness and achiness. Side effects usually occur one to two days after vaccination. Severe side effects and allergic reactions are rare. In past years, a small number of people who received the flu shot developed oculo-respiratory syndrome (ORS). ORS can cause red eyes, cough, chest tightness, difficulty breathing, hoarseness, sore throat and swelling of the face. Symptoms occur within 24 hours and resolve within 48 hours. In very rare instances (about one in one million doses of vaccine), the flu shot has been associated with a temporary neurological condition causing muscle paralysis called Guillain-Barré Syndrome (GBS). Seek medical attention if you believe that you, or someone in your care, had a reaction to the shot.

#### Who should not get the flu shot?

- People with a severe allergy to eggs or any component of the vaccine (e.g., neomycin, thimerosal) or who had a serious allergic reaction to a previous dose of influenza vaccine
- Babies younger than six months of age
- Any person who has had Guillain-Barré Syndrome (GBS) or who has an active neurological disorder should speak with a doctor before getting vaccinated.
- Most people who have had oculo-respiratory syndrome (ORS) can be safely reimmunized with the flu shot but should discuss this with a doctor first.
- Anyone who is ill with a fever should delay receiving the flu shot until they feel better.

What should I do if I get the flu? Get plenty of rest and drink lots of fluids. Wash your hands often. Stay at home and away from children, the elderly and anyone with a serious illness until you are feeling better. Ask your doctor about medication to reduce aches, pain and fever. Also ask about anti-influenza drugs that may ease your discomfort and shorten the length of your illness. Children should not be given medication that contains acetylsalicylic acid (e.g. aspirin) because it can cause Reye's Syndrome, a sickness that can lead to brain and liver damage. For more information, talk to your doctor or call Toronto Public Health at 416-338-7600.

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# **FLU ALERT**

# Influenza-like illness symptoms



Use this list on a daily basis to assess your family's health status.

Do you h	ave:
----------	------

Fever (over 38°C / 100°F)

Cough

Sore Throat

Joint pain or muscle aches

Fatigue or weakness

Headache

Yes

No

Yes

No

Yes

No

Yes

No

If you checked yes to **fever and cough AND one or more of the other symptoms** you probably have an influenza-like illness.

**Note:** In children under five years of age, vomiting or diarrhea may also be present, but not necessarily fever.

If you are ill, stay home.

If you have any concerns about you or your child's health, please contact your family physician or call

TeleHealth Ontario at 1-866-797-0000 (24 hours a day/7 days a week.)

416.336.7600 toronto.ca/health 111

**11 Tourist No** Public Health

# 2011 LET'S BEAT THE FLU 2012 Protect Yourself. Protect Your Family.

#### Free Flu Shots are available

	North Region Clinics	South Region Clinics	East Region Clinics	West Region Clinics
Thurs. Oct. 27		Alrium on Bay 506 Bay Street 11:90 a.m. – 5:00 p.m.		Shorway Gardons 25 The West Muli 2:30 p.m 8:00 p.m.
Fri. Oct. 28	Centerpoint Mail 6600 Yonga St. 2-50 p.m 8-00 p.m.	Abrium on Bay 506 Bay Street 11:00 a.m 5:00 p.m.	Scarborough Town Centre 30t Berough Dr. 3:50 p.m. – 8:90 p.m.	Shorway Gardens 25 The Wast Mali 2:30 p.m 0:00 p.m.
Set. Oct. 29	Centerpoint Mail 660) Yonga St. 11:00 z.m. – 5:00 p.m.		Scarborough Town Centre 300 Berough Dr. 11:00 a.m 5:00 p.m.	Etoblicoko Civic Centro 399 The West Mali 11:00 a.m 5:00 p.m.
Thurs. Nov. 3			Scarborough Civic Centre 158 Barough Drive 2:00 p.m. – 8:00 p.m.	Control of the Contro
Fri. Nov. 4	Lawrence Square Shopping Centre 700 Lawrence Avenue West 2:50 p.m. – 6:00 p.m.		Splondid China Towar Maii 4575 Stolos Avo., E 7:90 p.m. – 8:90 p.m.	Cloverdale Mail 250 The East Mail 2:30 p.m. – 3:00 p.m.
Sat. Nov. 5	Lawrence Square Shopping Centre 700 Lawrence Assnus West 1150 a.m. – 550 p.m.	Gorrard Square 1000 Sarrard Street East 11:00 a.m 5:00 p.m.	Splandid China Towar Mail 4675 Stokes Avs., E. 11:00 a.m. – 5:00 p.m.	Cloverdinio Mnili 250 The East Mnil 11:00 a.m. – 5:00 p.m.
Wed. Nov. 9		Motivo Halli 55 John St. 10:90 a.m. – 3:90 p.m.		
Thurs. Nov. 10		Motivo Hall 55 John St. 10:90 a.m. – 3:00 p.m.	Scarborough Civic Centre 158 Berough Drive 2:00 p.m. – 8:00 p.m.	
Set. Nov. 12	Yorkgate Mall 1 Yorkgate Blvd. 11:00 a.m. – 5:00 p.m.	East York Civic Contro 850 Corvell Avens 11:00 a.m. – 5:00 p.m.		Etoblicolo Civio Centre 399 Tho West Mall 11:00 a.m. – 5:00 p.m.
Fri. Nov. 18	North York Civic Centre 5100 Yongs Street 7-50 p.m. – 8:00 p.m.			Etoblicoke Civic Centre 309 The West Mall 2-90 p.m. – 8-00 p.m.
Sat. Nov. 19	North York Civic Centre \$100 Yongs Street 11:50 a.m 5:00 p.m.	East York Civic Contro 850 Corwell Avenue 11:00 a.m. – 5:00 p.m.		
Tues. Nov. 22		Toronto City Hall 100 Queen St. W. 10:00 a.m. – 3:00 p.m.		
Wed. Nov. 23		Toronto City Hall 100 Quan St. W. 10:00 a.m. – 3:00 p.m.		
Fri. Nov. 25	Parkway Mail 85 Elismura Rd. 2-50 p.m. – 8:00 p.m.		Scarborough Civic Centre 150 Borough Drive 2:00 p.m. – 8:00 p.m.	Etoblicoko Civio Cembro 399 The West Mali 2-90 p.m. – 8-00 p.m.
Sat. Nov. 26	Parkway Mall 85 Eleanum Rd. 11:00 a.m. – 5:00 p.m.		Scarborough Civic Centre 150 Barough Drive 11:00 a.m 5:00 p.m.	Etoblooko Civio Centro 399 The West Mail 11:90 a.m 5:00 p.m.
Thurs. Dec. 1		Motro Hall 55 John St. 10:00 a.m 2:00 p.m.		
Sat. Dec. 3		East York Civic Contro 950 Corwell Avenue 11:00 a.m. – 5:00 p.m.	Scarborough Civic Centre 150 Berough Brite 11:00 a.m. – 5:00 p.m.	
Sat. Dec. 10	North York Civic Centre 5100 Yorgs Street 11:50 a.m 5:00 p.m.	East York Civic Contro 850 Corwell Avenue 11:00 a.m 5:00 p.m.	Scarborough Civic Centre 158 Boxugh Drive 11-00 a.m 5-00 p.m.	Etoblooke Civic Centre 399 The West Mail 11:00 a.m. – 5:00 p.m.
Mon. Jan. 16		East York Civic Centre 850 Cervell Avense 2:00 p.m. – 8:00 p.m.		
Tues, Jan. 17			Scorborough Civic Centre 158 Bossigh Erive 2-00 p.m. – 8-00 p.m.	
Wed. Jan. 18	North York Civic Centre 5100 Yongu Street 2:00 p.m. – 8:00 p.m.			- Control of the Cont
Thurs. Jan. 19				Etoblcoke Civic Centre 929 The Wast Mail 2-90 p.m. – 8-60 p.m.

1-877-844-1944

toronto.ce/health



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## Pushed out of hospital while still acutely ill?

http://ochu.on.ca/senior care.html

Call the hotline: 888-599-0770

Patients who are acutely ill are being forced out of hospital. Some are pushed into unregulated for-profit retirement homes which have no standards of care. A man discharged from a Toronto hospital unable to feed himself starved to death in such a home last year. A dying Windsor woman was told care in a for-profit retirement home would be better than the care in hospital. Some patients are pushed out with the promise of homecare, much of which proves to be non-existent.

This hotline is for family members and former patients to call in to talk about their experience. We plan to hold a series of media conferences with the people who call, if they are willing to step forward. We plan to issue a report after the provincial election which will challenge the ongoing hospital bed cuts which are driving this phenomenon. We will also support a legal challenge alleging discrimination in the provision of care based on age.

Ontario Hospitals: Bed Cuts and Hospital Overcapacity: Over the last twenty years 18,581 hospital beds have been cut in Ontario. That is over 37% of total hospital bed capacity:

- Since 1980, over 30,000 hospital beds have been cut a cut of 50%.
- In 2010, 610 hospital beds were cut, about 2% of hospital bed capacity.

Far Fewer Beds Per Capita: A new health care report from the Organization for Economic Cooperation and Development (OECD) indicates that the average number of hospital beds per capita of its 34 member countries was 5.14 beds per 1,000 population in 2008. Canada has an average well below the OECD rate: 3.3 beds per thousand population in 2008. That's about 64% of the 2008 OECD average. The OECD represents the most economically advanced countries in the world.

**Ontario Lower Still:** Ontario, however, is in a different league. In 2009, Ontario had a rate of 2.41 beds per 1,000 population, well less than half the OECD average and less than three-quarters of the Canada-wide average. In fact, Ontario has fewer hospital beds per capita than any other province.

Of all OECD countries, Ontario only managed to edge out Mexico and (possibly) Chile (pending final 2009 figures for Chile). Turkey increased its beds in 2009 pulling a little ahead of Ontario to 2.5 beds per thousand.

In 2010, Ontario's beds per thousand fell further to 2.33 per thousand. The announced health care funding plans will mean more bad news after the provincial election. The situation is worse for acute care beds. Here, Ontario has a lower number of acute care beds per capita than any developed country, Chile and Mexico included. Indeed at 1.39 beds per thousand population we are 15% behind the next lowest country (Mexico at 1.6).

We truly are an outlier, well below the Canadian average (of 1.8 in 2008), and far below the OECD average (of 3.6 in 2008). Canada as a whole has 27% more acute care beds per capita than Ontario (using the 2008 data), while the OECD countries have, on average, 154% more. Ontario also has the lowest average length of hospital stay of all provinces and has the fewest acute care hospitalizations per capita of any province.

Lack of Rehabilitation and Complex Continuing Care Beds: There was a total of 853,316 alternative level of care (ALC) days in Ontario hospitals in 2007-8. Mostly, these were for patients waiting for a different sort of bed. The report indicates that 27% of those days are accounted for by patients who were waiting for a complex continuing care or rehabilitation bed.

Rehabilitation and complex continuing care beds are different sorts of hospital beds, so this suggests the resolution of the ALC issue will need improvements in the capacity of Ontario hospitals in those areas.

A further 13% of days were accounted for by patients who died while in an ALC bed: this group was almost always either waiting for a palliative care bed, or waiting for another sort of bed.

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**Bed Occupancy moves to the stratosphere:** Not surprisingly, Ontario has very high bed occupancy rates: currently about 97.9%. The British Medical Association connects high hospital bed occupancy with increases in hospital acquired infections. Britain aims to keep hospital bed capacity at less than 85%. Other countries have lower bed occupancy rates.

Canada has the highest level of acute care bed occupancy in the developed world and has one of the highest rates of health care acquired infections ("HAIs" e.g. C. Difficile or MRSA) in the developed world according to World Health Organization data. The only country reported to have a higher level of health care acquired infections is New Zealand - -which also has a very low number of hospital beds per capita.

Bed cuts and high hospital bed occupancy has been associated with:

- intense pressure to move patients out of hospitals, often to inappropriate for-profit retirement homes, or by threatening patients with very high fees;
- cancelled surgeries;
- backlogs in emergency rooms;
- ambulance offload delays;
- fewer ambulances available to respond to emergencies;
- extra costs for municipal providers of ambulance services;
- delays in treatment and diagnosis;
- a high number of patients waiting in hospital beds for more appropriate hospital services;
- attempts by advocates of privatization to move public hospital services to for-profit provide.



# Aging in Our Co-op Communities: A Survey of Housing Co-ops in Canada (2011)

**Published by the Canadian Housing Federation** 

The survey, produced by the Co-Operative Housing Federation of Canada (CHF), provides important insight into the strengths and challenges housing co-ops and members face as they age in their co-op homes.



The purpose of this project was to develop a unified picture of seniors in co-op communities and identify specific areas of need. The survey data creates a clear picture of the value of living in co-operative housing as described by the more than 450 older co-op members who participated in the survey.

#### The survey found:

- 1. Older co-op members value and are satisfied with co-operative living. The surveys found that housing co-operatives work very well for older co-op members in terms of the quality of housing and services received, and the social benefits.
- 2. Older co-op members are involved in the governance of their co-op homes.
- Most co-op members and housing co-ops have not made plans that include an aging membership.
- 4. There is a shortage of appropriate accessible units for older members within the existing co-op housing stock.

**Conclusion:** Over the next few years the number of older members in housing co-ops will grow. Housing co-ops need to be ready so that they remain a good place for older members to live. The demand for both simple and more complex modifications to units and programs that support older members will also increase. One of the biggest challenges ahead will be the end of government subsidies that support low-income households.

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## **Gateways Gets Published Yet Again**

**By: Carling Barry** 

The Gateways Team would like to announce that the Gateways Project has been published in The Journal of Cancer Education, Volume 26, Number 4, entitled 'Access to Cancer Screening for Women with Mobility Disabilities'.

This scholarly article outlines the focus group participants identifying the multiple and interacting institutional barriers to cancer screening. Their discussions highlighted the complex work of:

- (1) arranging and attending health-related appointments,
- (2) confronting normative assumptions about women's bodies and
- (3) securing reliable health care and information.



These issues interact to shape how women with disabilities access and experience cancer screening. The article explores implications for redesign of cancer screening services and education of health providers, providing specific recommendations suggested by Gateways participants and the findings.

## Gateways: A Recap and Update

By: The Gateways Team

In 2006, the Centre for Independent Living in Toronto (CILT) Inc. recognized the need to explore and understand the cancer screening experiences of women with mobility disabilities. Partnerships were then developed with disability activists, university-based health researchers and health professionals in Toronto:

- Centre for Independent Living in Toronto
- Canadian Cancer Society
- Mount Sinai Hospital
- Ismaili Cancer Support Network
- Springtide Resources
- Faculty of Nursing, University of Toronto



#### Gateways I Project (2006-2008):

<u>Purpose:</u> To explore the breast, cervical and colorectal cancer screening experiences and care needs of women with mobility disabilities in Toronto.

#### Methodology:

- Initially conceived as qualitative descriptive research
- Conducted as a community-based, participatory action research project (PAR)

#### Participatory Action Research (PAR):

- PAR involves all relevant parties examining together current action (which they
  experience as problematic) in order to change and improve it.
- PAR is not just research which is hoped that will be followed by action. It is action
  which is researched, changed and re-researched, within the research process by
  participants.
- PAR aims to be active co-research, by and for those to be helped.
- PAR tries to be a genuinely democratic or non coercive process whereby those to be helped, determine the purposes and outcomes of their own inquiry (much like the Independent Living philosophy). [Wadsworth, 1998]

## **Gateways I Project Results:**

- Focus groups were conducted by peer researchers with 24 women with mobility disabilities from diverse communities in the Greater Toronto Area (GTA)
- Key findings: women with disabilities face architectural, systemic and attitudinal barriers to effective screening.
- Recommendation: disability training for healthcare professionals and clinical staff who work in cancer screening on appropriate and clear communication, compassionate behaviour and best practices.

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#### Our Current Initiative: Gateways II Project (2009-2012)

In 2009, the Gateways Team applied for and received a community-based research implementation grant from the Canadian Breast Cancer Foundation for a new project...

Improving the Breast Cancer Experience for Women with Mobility Disabilities:
An Educational Intervention with Healthcare Providers (Gateways II)

#### Gateways II Team:

- Mount Sinai Principal Investigator
- Mount Sinai Project Manager
- Mount Sinai Research Associate
- Mount Sinai Curriculum Developer
- Centre for Independent Living in Toronto
- Ismaili Cancer Support Network
- University of Toronto, Faculty of Nursing
- Springtide Resources
- Ontario Breast Screening Program

#### Project Purpose:

- Address barriers to accessing breast cancer screening for women living with disabilities.
- Improving the mammography experience for women living with disabilities.
- Develop, implement, evaluate an innovative, evidence-based education strategy for healthcare professionals to increase their competencies when working with women with mobility disabilities.



<u>Methodology:</u> Principal Investigator-led model of education research and implementation, supported by an Advisory Group.

#### Project Overview:

- Phase 1: Qualitative research study to learn about the experiences, perceptions
  and learning needs of healthcare providers working in breast cancer screening
  around providing care for women with mobility disabilities.
- **Phase 2:** Development and delivery of a disability education program for healthcare providers at a cancer screening centre in Toronto.
- Phase 3: Evaluation of the education program and production of other educational materials.

Anticipated challenges to maintaining a community-based qualitative action ideology within an institutional setting:

- **Building team cohesion/trust** introduction of new team members, greater institutional representation on team.
- Sharing power and control Principal investigator (PI)-led decision making, negotiating institutional rules, regulations and requirements.
- Maintaining engagement and involvement of all team members.

# Representing Disability in Health Provider Education: Overcoming Ethical Challenges

In part one of Gateways, women with mobility disabilities were asked to participate in focus groups to discuss their personal experiences with healthcare providers when accessing cancer screening.

In part two of Gateways, focus groups were held with healthcare providers to hear about their experiences, concerns and feelings when screening women with mobility disabilities. In doing so, the Gateways Team wanted to find out healthcare

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professionals' learning needs about providing care for women living with mobility disabilities.

Focus groups were held with 43 healthcare providers from the Joint Department of Medical Imaging at three different academic teaching hospitals in Toronto: Mount Sinai, Women's College and Princess Margaret. Separate focus groups were held with clerical staff, mammography technologists, and radiologists from each hospital between April and June 2010. Data was then analyzed from each of the focus groups.

#### Focus Group Questions asked:

- Icebreaker question: When I say the word 'disability', what comes to mind?
- Tell me about any experiences you have had while caring for people with disabilities?
- What have these experiences been like for you as a healthcare professional?
- What do you think these experiences were like for the person with a disability?
- What did you learn from the interaction?
- Based on your experiences, what are some ways to improve the experience for these patients?

Information gathered from all focus group sessions was coded and analyzed in order to come up with some underlying themes. For example:

- Internal Barriers: normative assumptions, healthcare providers' attitudes and Knowledge, Architectural, Equipment, Human Resources, Systemic Constraints, Communication Constraints
- External Barriers: Transportation, Equipment, Support Constraints, Patients' Attitudes and Knowledge, Participation and Experience, Anxiety, Communication Constraints, Past Negative Experiences

 Facilitators: Providers' Attitudes and Knowledge, Participation and Experience, Patients' Attitudes and Knowledge, Participation and Experience, Notice and Knowledge, Internal Communication, Patient Communication, Volunteer/Caregiver Assistance, Systemic Improvements

Learning Needs: Communication, Disability Education, Clinical Education

#### Results:

#### I WANT TO HELP, BUT, WHAT DO YOU DO IN A SITUATION LIKE THAT?

#### **Health Care Providers:**

- Care about patients and empathize with the fear and anxiety patients may be feeling when they come for breast cancer screening.
- Recognize the need to treat patients with disabilities as people.
- Recognize that offering help, communicating well, being patient, and being encouraging to patients with disabilities is important for their comfort.
- Recognize that screening is a collaborative activity.
- Understand that patients with disabilities are knowledgeable about their own bodies; staff must ask questions, listen, and follow their lead.

# <u>Examples of things Healthcare Providers do to provide appropriate care for women with disabilities:</u>

- Book patients for less busy or longer appointment times
- Pre-book ultrasound in case it is necessary
- Expedite appointment (particularly if patient arrives by Wheeltrans)
- Direct patients to larger change rooms, assist with changing, toileting, and completing forms as necessary
- Communicate more deliberately and talk patients through the mammography procedure

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#### BUT WHAT DO YOU DO WHEN....

#### **WOMEN WITH DISABILITIES:**

- May vent their frustration over systemic issues to HCPs (Healthcare Providers)?
- Respond to assistance from HCPs in a mixed fashion, which is ultimately confusing and paralyzing?

#### **HEALTHCARE PROVIDERS:**

- Experience general discomfort and uncertainty about respectful and appropriate communication/interaction strategies for patients with disabilities?
- Find novel care situations challenging?
- Are concerned about suboptimal imaging?

Quotations from health care providers who participated in focus groups:

"I guess maybe sometimes, because a lot of them value their independence, I don't know how to ask certain questions without offending them. So, like, sometimes... you open a door for somebody and sometimes you get, like, 'Thank you', and then other times they'd kind of be like, 'Well, I can open the door myself'. That kind of thing, you know? Them thinking that I feel sorry for them kind of thing."

"So I have my experience, and I know what P3 was saying in terms of, like, you don't want to cross the line and say, 'oh, do you need help' too much. And you do want to assist them. Sometimes at the desk, like when you're checking them and you see the double doors they have to go through, and you're sitting there. It's like, you want to run and go open the door, but then you don't want to... you know what I mean, you don't want to cross the line by asking, 'can you get the door?'. It's a little bit hard."

Successful mammography screening requires good provider and patient interaction (active engagement and participation during procedure):

- Patients with cognitive impairments may not understand or be able to actively participate in procedure, which is stressful and difficult for health care providers
- Some patients will not actively participate in the procedure, which is stressful and difficult for health care providers.

#### **Health Care Providers:**

- Make a lot of (stereotypical) assumptions about what patients are thinking, feeling, and experiencing: ex. anxiety and frustration is about fear of cancer, being a "burden", the hassle of screening, and transportation issues, rather than other barriers and stressors
- Receive little or no training about how to care for patients with disabilities.

When health care providers were asked how much training they receive on disability issues, some of them said:

"There was no formal training about disability. I think I just learned... There was more, like, regulations and procedures. The rules of what you should do or not do. It doesn't tell you, like, when you do one on one patient care, how can you help the patient the most. Or make them feel more comfortable or how to read their anxiety. That was just more like, 'this is what the government says'. So that wasn't as helpful."

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#### Final Results of Gateways II:

The final product of the Gateways Project will be a Disability Education Program which will:

- Bring the voices, needs, and lived experiences of service-users into the walls of an institution in the form of a training video;
- Assist healthcare providers to develop embodied empathy for women with disabilities Improve the mammography experience of women with disabilities who get screened for breast cancer; and to
- Promote health equity for women with disabilities accessing cancer screening.

The Gateways Team has recently hired a well-experienced individual who has filmed many teaching videos such as this one. The DVD will be approximately 13-15 minutes in length and will include women with disabilities talking about their cancer screening experiences as well as a health care provider talking about their experiences around screening women with mobility disabilities. It's all very exciting. We will keep you updated as further results enfold.





## **Depression and Disability**

#### By Karla Thompson, Ph.D

Depression is not just feeling sad, "blue," or discouraged, and it is much more than the normal "downs" that can be a part of everyday living. It is an illness that affects the whole person – their thoughts, feelings, behavior, and physical health. In its mildest form, depression can keep otherwise healthy individuals from enjoying their lives to the fullest.



When depressive symptoms are more serious, they cause needless suffering for the person who is depressed and needless pain for the people who love them. In its most severe form, depression can be a life-threatening condition.

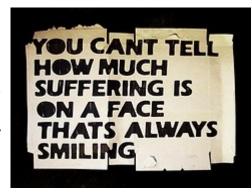
#### **Symptoms:** Some of the symptoms of depression can include:

- Feelings of sadness, anxiety, hopelessness, or emptiness
- Loss of interest in activities that used to be enjoyable
- Sleep problems, like sleeping too much, having trouble falling or staying asleep, or waking very early in the morning
- Changes in appetite with weight loss or weight gain
- Feelings of increased irritability, restlessness, or frustration
- Decreased energy or becoming tired after normal activities
- Difficulties with concentration, memory, decision making, or mental slowing
- Feelings of excessive guilt, worthlessness, or helplessness
- Decreased interest in interacting with others
- Crying more often than usual
- Recurring thoughts of death or dying
- Thoughts of suicide or suicide attempts

When someone is depressed, they have symptoms nearly all day, everyday, that last for at least two weeks.

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Not everyone who is depressed will have all of these symptoms. The individual symptoms of depression are very common. Occasional changes in sleep or appetite, or feelings of sadness, guilt, irritability, or fatigue are part of the normal human experience. It is when many of these symptoms occur together, cause difficulties in day-to-day functioning, and last longer than a few weeks that they may be signs of a depressive illness.



All kinds of depression are treatable. When someone is depressed, they have symptoms nearly all day, everyday, that last at least two weeks. There is more than one kind of depression.

The most severe kind of depression, called **Major Depression**, involves a specific combination of the symptoms described on page two. Sometimes Major Depression is part of another mood disorder called **Bipolar Disorder**, in which periods of depression alternate with periods of elevated mood, increased energy, agitation, and other symptoms.

People who are experiencing an episode of **Major Depression** often feel hopeless and overwhelmed. They may have trouble getting out of bed in the morning or taking care of themselves in other ways. For people with some kinds of disabilities, neglecting even the most routine aspects of self-care can lead to other, potentially life-threatening medical conditions, and depression is believed to be a contributing factor in many preventable deaths among individuals with disabilities. Suicide rates are also higher among some groups of people with disabilities.

Less severe kinds of depression include **adjustment reactions** and **Dysthymia**, a chronic, low-grade depression lasting two years or more. While Dysthymia is less likely to lead to suicide, it can be associated with persistent feelings of dissatisfaction, discouragement, and disappointment that contribute to a poor quality of life.

#### Why do people become depressed?

Depression isn't "all in your head." It is not a sign of personal weakness, and it is not caused by laziness or a lack of willpower. It is a real illness with real causes. Some of these causes include biology, heredity, personality, and/or life experiences.

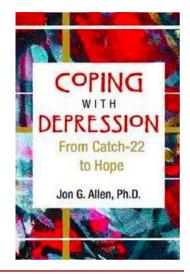
Depressive disorders involve chemical changes in the brain. People with depression typically have too much or too little of certain brain chemicals, called "neurotransmitters." Whether these chemical changes are always the primary cause of depression or occur after someone becomes depressed is a question that has yet to be answered. However, treatments that restore these chemicals to their normal levels help to cure symptoms of depression.

Some symptoms of depression can be caused by **chronic medical conditions** or the **medicines** used to treat them. For this reason, a complete physical examination and medical work-up should always be conducted before someone begins treatment for depression. **Alcohol or drug abuse** can also cause depressive symptoms.

**Depression tends to run in families**, and if anyone in your immediate family has problems with depression, you are at increased risk. **Women are twice as likely as men to experience depression.** The reasons for this may include hormonal changes associated with the female reproductive cycle or the stresses associated with being a woman in today's society.

Some **personality characteristics** and **coping styles** are also associated with depression. For example, having **low self-esteem** or feeling that you have **no control** 

over events in your life are common traits in people with depression. However, not everyone agrees whether these personality characteristics cause depression or are simply symptoms of depression.



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Any of these factors, alone or in combination, may place an individual at increased risk for depression. **Certain life events** may also trigger one or more episodes of depression.

Some theories about the causes of depression suggest that people who become depressed have had too many negative life experiences (like serious illness or the loss of a job) or too few positive, pleasurable experiences (like rewarding relationships with others). While some symptoms of depression are a natural response to stress or loss, the suffering and feelings of hopelessness associated with a clinical depression are typically more intense, last longer, and have a much greater impact on an individual's day-to-day functioning than the feelings associated with any one particular loss or life crisis.

#### Why are people with disabilities at risk for depression?

Having a disability doesn't automatically mean that you are going to become depressed. Not all people with disabilities suffer from depression, and for those who do, their depression may have little to do with their disability. However, depression is associated with certain life experiences that are more common among individuals with disabilities. In addition, people with disabilities face many unique problems and challenges which may place them at increased risk for depression.

## Some challenges that people with disabilities face:

MOBILITY: Many persons with disabilities have trouble walking or getting round, both in their own home and in the community. This can effect how they take care of everyday activities, like dressing or bathing, as well as how often they get out of the house. Sometimes having mobility problems means needing help from others to do things that most people can do on their own, which can be frustrating or embarrassing. Being unable to drive may further limit one's ability to participate in important life activities like work and play, as well as taking care of everyday tasks like grocery shopping or visiting with friends. Not having the strength, endurance, or other abilities necessary to do what you want to do, when and how you want to do it, may cause you to feel frustrated, angry or helpless.

ACCESSIBILITY: Because most homes and many buildings and ACCESSIBILITY businesses still do not meet the ODA guidelines for accessibility, FOR LIFE

individuals who move slowly or use wheelchairs, scooters, walkers, or canes may find it more difficult to shop, dine, work, or access health care and other professional services.

**SOCIAL BARRIERS:** Not all of the obstacles and barriers individuals with disabilities face are physical. Many people without disabilities don't understand what it's like to have a disability or don't know how to act around someone with a disability. In addition, some people feel uncomfortable or harbor prejudices and negative attitudes toward individuals with disabilities. These are social barriers that can make it more difficult for people with disabilities to form friendships and other relationships. Not having good social support increases anyone's risk for depression.

**EMPLOYMENT:** In general, people with disabilities may have more difficulty finding and keeping jobs. Sometimes this is because of the individual's physical or other limitations, and sometimes it is because of social prejudices and misconceptions. Whatever the reasons, difficulty finding and keeping work can lead to financial problems, which are an additional source of stress. Work is also an important source of self-esteem for many people. Not being able to work when you want to work may lead to feelings of worthlessness or guilt.

**HEALTH:** Many people with disabilities enjoy good health, but some kinds of disabilities are associated with more health problems, and sometimes persons with disabilities have trouble getting the health care they need. Even people who don't have disabilities are more likely to become depressed if they have many medical problems, and people with more symptoms of illness tend to suffer from more severe depression. Finding ways to pay for health care can also be especially difficult for people with disabling conditions.

Not all Disabilities are Obvious: Some individuals with disabilities look and move just like non-disabled people but have trouble hearing, speaking, seeing, reading, thinking, paying attention, or remembering. Other people with chronic illnesses may look well but have problems with pain, fatigue, or other disabling physical symptoms. These kinds of problems can make it difficult to work, go to school, take care of yourself, and communicate with others. They may be especially hard to deal with because people may not recognize that you have a disability or understand what you are going through.

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Any of these challenges are difficult to deal with. When someone has to deal with several of these at the same time, the risk for developing a depressive illness is greater. However, regardless of the cause or contributing factors, depression can be treated.

#### How is depression treated?

There are many effective treatments for depression available. With appropriate treatment, the majority of people with depression can feel better, often within a matter of weeks. Counseling or "talk" therapy, medications, or a combination of the two are the most common and effective treatments.

**Counseling or psychotherapy** helps people learn to cope with depression and to deal with personal and external factors that may be contributing to their depression. Some therapies focus on helping people identify and change attitudes or ways of thinking that contribute to their depression, while other therapies are designed to help people change their behavior.

**Antidepressant medications** are an important part of treatment for depression. These medications aren't "happy pills" or tranquilizers. They do not elevate mood by changing your personality or making you lose touch with reality, and they are not habit forming. They work because they help restore the chemical balance in the brain that is altered when someone becomes depressed.

Although the combination of talk therapy and antidepressant medication is an effective treatment for the majority of people with depression, sometimes more severe and persistent depressions require more aggressive treatments. These may include hospitalization and/or electroconvulsive therapy.

## What should you do if you think you are depressed?

Depression is very treatable, but too often, people with depression don't get help. This may be because they don't recognize that they are depressed, have trouble asking for help, or are embarrassed or blame themselves for how they feel. Other people mistakenly think that they will just "snap out of it," and some don't know that help is available. If you think that you or someone you care about may be depressed, get help. Have yourself evaluated for depression so that you can get the appropriate treatment for you and be on your way towards feeling more like yourself again.

People and places you can contact for help include your family doctor and your local hospital, public health clinic, or mental health centre.

If your depression is so severe that you are thinking about suicide, don't wait around hoping to feel better. GO TO YOUR LOCAL EMERGENCY ROOM.

Sometimes people get so depressed that they can't make themselves get the help they need. If you think someone you care about is severely depressed, don't leave it up to them to get help. Help them make an appointment to talk with their doctor or a mental health professional, and make sure they keep that appointment.

#### What Else Can You Do to Feel Better?

If you have a serious depression you should **seek help from a competent mental health professional**. However, there are also a number of things you can do to help yourself feel less alone, discouraged, or blue. If you don't think you are depressed but do feel down at times, these are things you can do to feel better and reduce your risk for developing a serious depression.

**Talk to friends or family** about what you are feeling. Feeling sad or disappointed in life is nothing to be ashamed of, and sometimes just letting people know that you are feeling down can help you begin to feel better. The people who care about you can't help you if they don't know what you're going through. If you can't get out of the house to see friends and family, write a letter or talk with them on the telephone.

Get in touch with other people with disabilities. As much as they may try, non-disabled people can't always understand what it's like to live with a disability. If you are feeling alone or misunderstood, **talking with someone who has a similar disability** can make all the difference in the world. Your health care provider may be able to give you the names of other individuals who have had similar experiences.

**Support groups** for individuals with specific disabilities can also be an important source of information on how to cope with disabling conditions, for example local support groups for brain injury, stroke, spinal cord injury, spina bifida, multiple sclerosis, and other disabling conditions. **Public libraries** in some areas have computers which can be used to **search the Internet** for groups and agencies that provide education

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and support for individuals with disabilities.

**Become an Advocate:** If you think that environmental and social barriers are causing you to feel discouraged, down, angry, or bad about yourself, find out what you can do to make a difference. Find out about **local advocacy groups**. Talk to store managers who make the aisles in their stores too narrow for wheelchairs. Tell your doctor or the local hospital that they need more handicapped parking spaces.

Write your local Member of Parliament about the problems with health care and that individuals with chronic disabling conditions can face. And respond directly - but with dignity- when people who don't know better behave poorly or use language that offends you when talking with you about your disability.

**Exercise:** Physical activity can be one of the most effective ways to combat depression. Even if you have significant physical limitations, increasing your level of physical activity even just a little bit will help improve your mood.

**Stress Management:** Although stress doesn't always cause depression, stress tends to make depression symptoms worse. Finding stress management techniques that work for you - relaxing, meditating, praying, watching funny movies, doing crafts, keeping a journal, or any other activities that make you feel less stressed - can make you less vulnerable to depression.

**Volunteer:** Volunteering can be a meaningful and rewarding way to spend your time. It can get you out of the house and provide opportunities for interacting with others. If you can't get out of the house, you can still make telephone calls, write letters, or do other kinds of volunteer activities from your home. Spending time and energy helping others can help take your mind off your own troubles and make you feel appreciated by others.

## For more information:

Centre for Addiction and Mental Health: 416-535-8501

Telehealth Ontario: 1-866-797-0000 Connex Ontario: 1-866-531-2600



# Centre for Independent Living

Access HEALTH is a quarterly publication.
Editor: Nancy Barry

365 Bloor Street East, Suite 902 Toronto, ON M4W 3L4

Phone: 416-599-2458, x227

Fax: 416-599-3555

Email: peervolunteer@cilt.ca

We're on the Web! www.cilt.ca



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Voir au-delà du handicap Promoting a new perspective on disability