

# Thinking Ahead in Palliative Care

Annual Conference 2011



Supporting  
each other in  
the age of  
austerity and  
social media



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Facebook, Twitter and Skype: ajadad  
LinkedIn: alexjadad  
Cell phone: +1 416 358 5631

# In 1996: A prescient message...



## *About This Homepage*

My name is Melinda Rose Hathaway, I am 15 years old, I live in Western Canada, and I have [cancer](#).

I created [this page](#) so that I could do at least a little something to help provide other Cancer Kids and their caregivers (especially those who are newly diagnosed) with hope, with access to some of the important information that they might be looking for, and with contact to other Cancer Kids, caregivers, and cancer related sites all over the world. After all ... isn't that what the World Wide Web is really all about?

I would also like to help you get to know me better ... as a *real person* and not just as a girl with cancer. If you have the time, I'll tell you about some of the things that I am interested and involved in, you can read some of the poems that I have written and the artwork that I have created over the past two and one half years, and you can even visit some of the sites that I like the best.

# How could we harness what we have?

9 July 2010 Last updated at 07:23 ET



## Over 5 billion mobile phone connections worldwide

**More than a billion mobile phone connections have been added to the global tally in just 18 months, according to Wireless Intelligence.**

There are now more than five billion connections worldwide.

In many regions, penetration exceeds 100%, where there is more than one connection per person in the country.

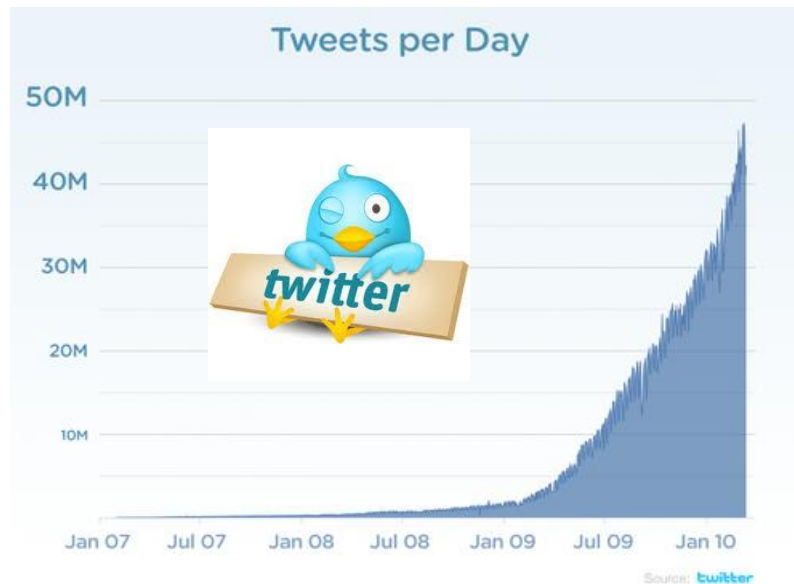
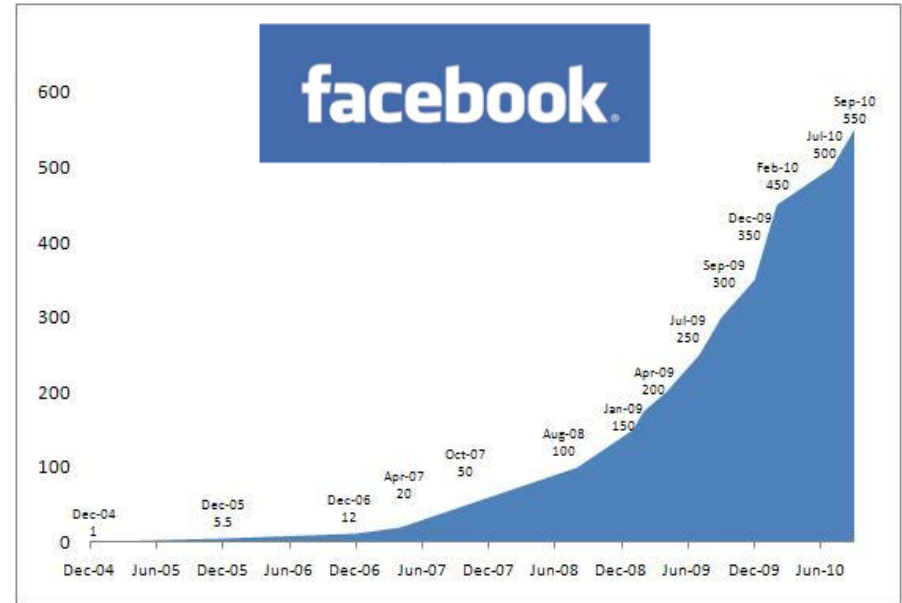
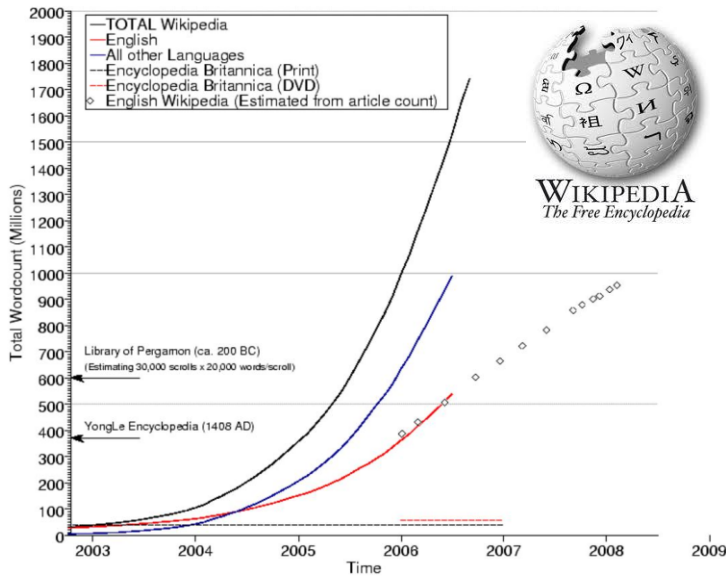
Ben Wood, mobile phone analyst at CCS Insight said the mobile phone may be "the most prolific consumer device on the planet".



Mobile phones have taken the world by storm

Source: International Telecommunication Union

# Unprecedented levels of exponential change...



# The world in our hands...



# Getting better every day!



iPad



# What do we want to achieve?

**BMJ** helping doctors make better decisions

Published 10 December 2008, doi:10.1136/bmj.a2900

**Cite this as:** BMJ 2008;337:a2900

## Editorials

### How should health be defined?

Join a global conversation at <http://blogs.bmj.com/bmj/2008/12/10/alex-jadad-on-defining-health/>

Alejandro R Jadad, *professor*, Laura O'Grady, *postdoctoral fellow*

# BMJ

343: 295-266 No 7817 Clinical research ISSN 0959-8138  
30 July 2011 | bmj.com

**PLUS** Patient's journey: dementia

Type 2 diabetes and tight control

Bleeding and coronary stents

Lost in transliteration

**JOBS, COURSES, AND CAREERS**



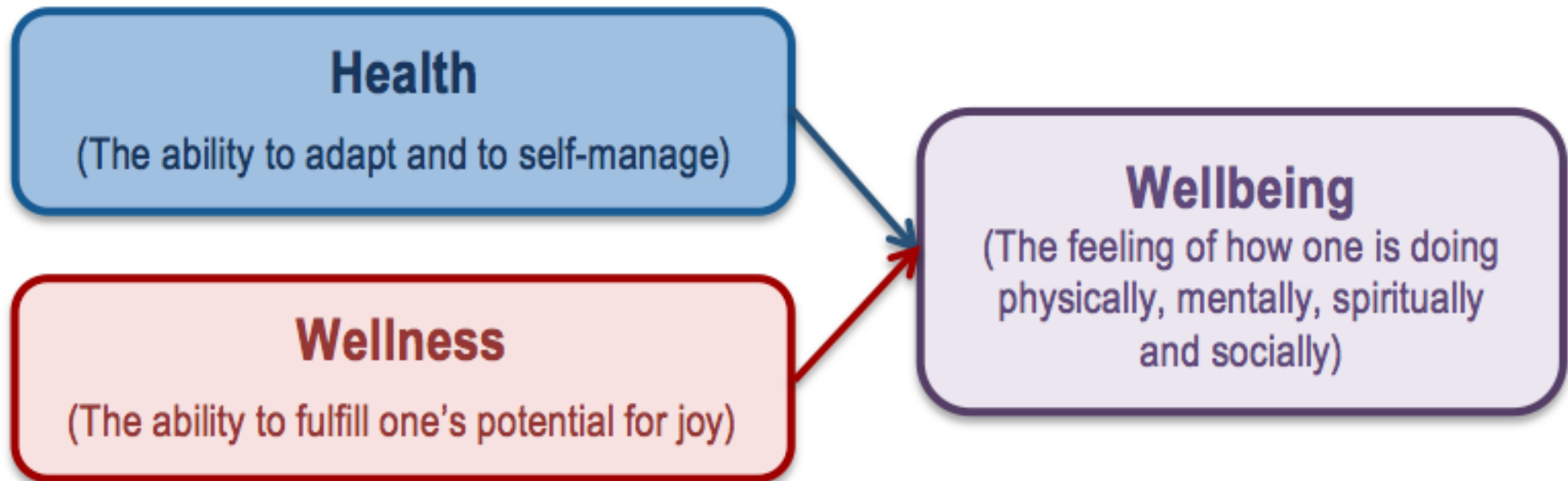
# HEALTH

## TIME FOR A NEW DEFINITION?

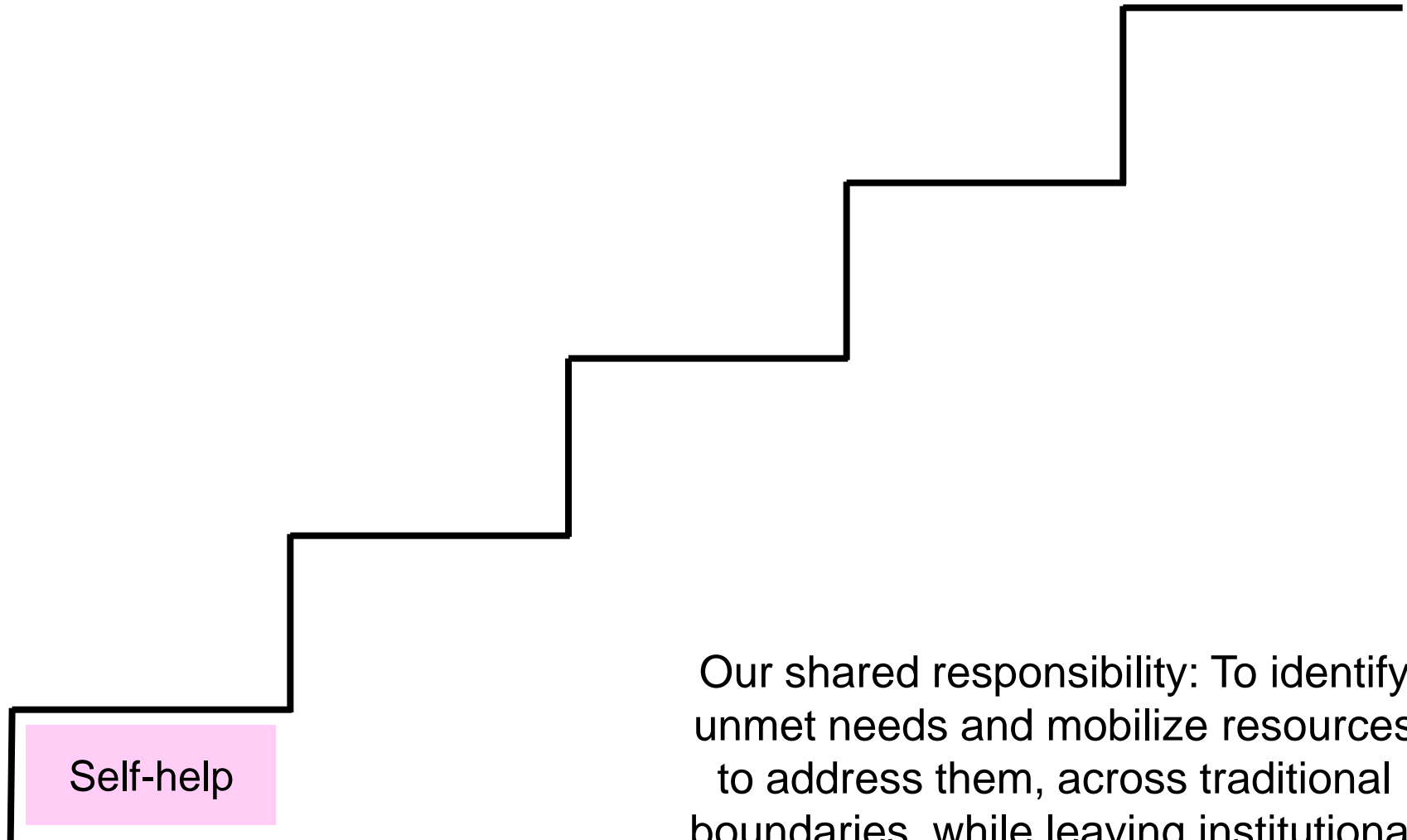
**HEALTH** noun ['helth]

The capacity of an individual and a community of people to adapt and direct their own lives in the face of social, physical and emotional challenges

# We must be reactive...and also proactive



# The staircase of support



Our shared responsibility: To identify unmet needs and mobilize resources to address them, across traditional boundaries, while leaving institutional care as the last resort

# Over 15 million hits!



palliative care



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[Palliative care - Wikipedia, the free encyclopedia](#) 🔍

**Palliative care** (from Latin palliare, to cloak) is a specialized area of healthcare that focuses on relieving and preventing the suffering of patients. ...

[Concept](#) - [Comparison to hospice in the ...](#) - [Goals](#) - [History](#)

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**Palliative care** is specialized care focused on the pain, symptoms and stress of serious illness. Find a hospital or medical center in your area that has a ...

[Provider Directory](#) - [Palliative Care vs. Hospice Care](#) - [Quick Facts](#) - [Videos](#)

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**Palliative care** (different from hospice care) is medical care provided by physicians, nurses and social workers that specializes in the relief of the pain, ...

[www.getpalliativecare.org/whatis](http://www.getpalliativecare.org/whatis) - [Cached](#) - [Similar](#)

[News for palliative care](#)



NorthernLife.ca

[What Is Hospice? | Philadelphia Inquirer | 2011-04-04](#) 🔍

2 days ago

Using **palliative care**, hospice focuses on easing symptoms, rather than curing a disease. Studies show that patients receiving this type of care often live ...

[Philadelphia Inquirer](#) - [55 related articles](#)

# A good opportunity to make a difference...



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The Free Encyclopedia

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`'''Palliative care''' (from [[Latin]] 'palliare' to cloak) is a specialized area of healthcare that focuses on relieving and preventing the suffering of patients. Unlike [[hospice care]], palliative medicine is appropriate for patients in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients who are nearing the end of life. Palliative medicine utilizes a multidisciplinary approach to patient care, relying on input from physicians, nurses, chaplains, social workers, psychologists, and other allied health professionals in formulating a plan of care to relieve suffering in all areas of a patient's life.`

`==Concept==`

`A recent [[World Health Organization]] statement<ref>{{cite web | title=WHO Definition of Palliative Care | publisher=[[World Health Organization]] | url=http://www.who.int/cancer/palliative/definition/en/ | accesdate=March 7, 2006 }}</ref> describes palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." More generally`

# Large economies of scale are emerging

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4 April 2011 Last updated at 05:22 ET

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## Cancer charity 'tidies' Wikipedia

Cancer Research UK is turning its specialists loose on the internet to get them to tidy up the online encyclopedia - Wikipedia.

The charity said many people researching the subject are turning to the website.

But it said there were problems with accuracy and clarity on some of the pages.

Wikipedia said it encourages experts to edit the site as they have a lot to contribute.



Cancer Research UK cleaning up Wikipedia

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**Depression and Anxiety  
Coping Strategies**

by MarksPsych

613 views

6:03



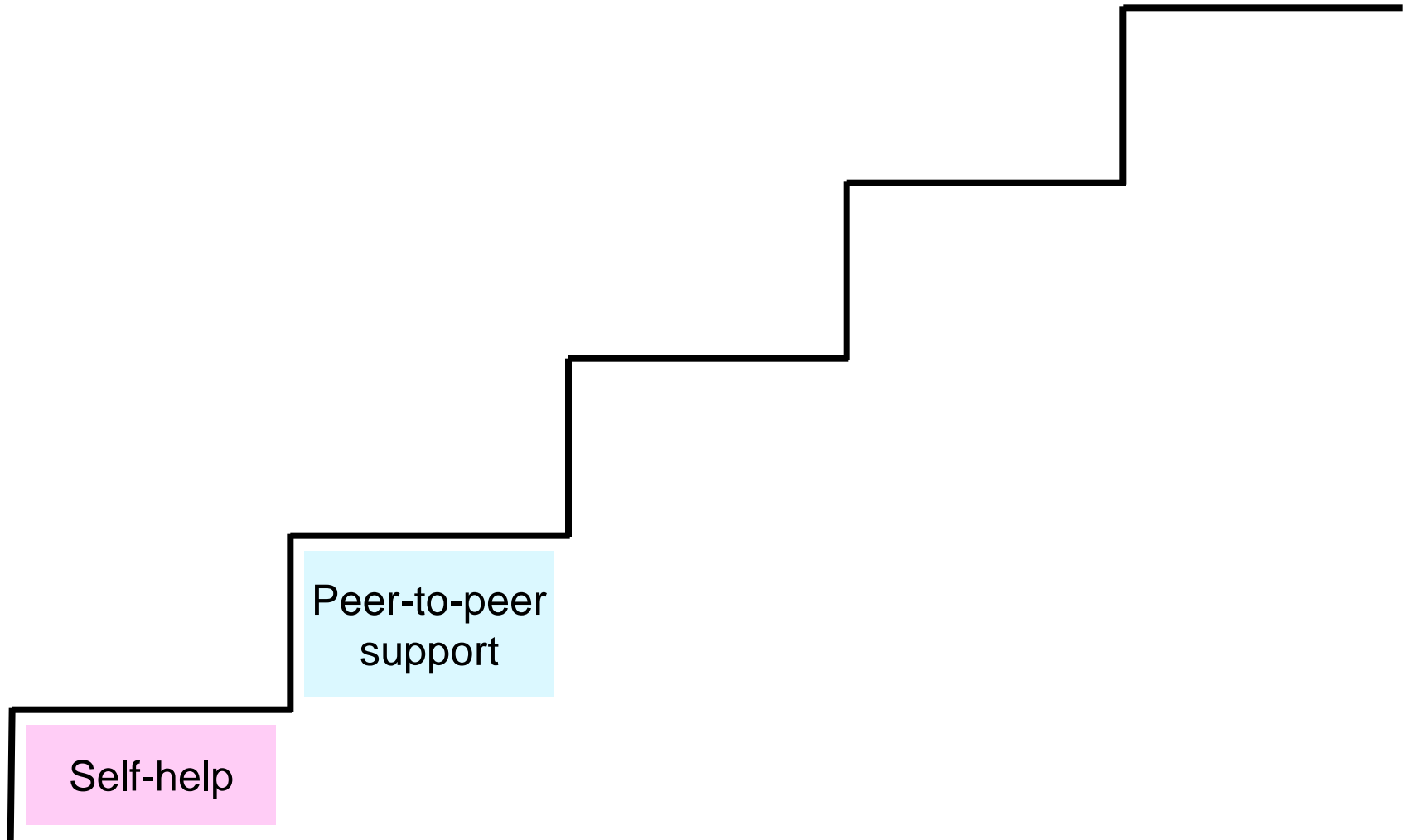
**Coping strategies**

by Ethnosnacker

350 views

4:43

# The staircase of support







# Seeking symptom relief...

facebook Home Profile Friends Inbox 7 Alex Jadad Settings Logout Search

breast cancer Search

Show: All Group Types Sponsored Results

All Results  
People  
Pages  
Groups  
Applications  
Events  
Web Results  
Posts by Friends  
Posts by Everyone

**Total search yield  
n=637**

- **Fundraising 45%**
- Awareness 38%
- Support-a-site 10%
- Support 7%

**Groups analyzed  
n=621**

# Through the entire continuum of care...



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Forums



Online Grief Support, Help for Coping with Loss | Beyond Indigo Forums

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## How do I \_\_\_\_\_ on the forum?

Forum	Stats	Last Post Info
 <b>Help/Questions</b> The forums have changed! Bring any questions you have here!	12 Topics 54 Replies	→ 24 March 2011 - 05:59 AM <b>In:</b> How do i _____ on the forums? <b>By:</b> ModKonnie

## Loss of....

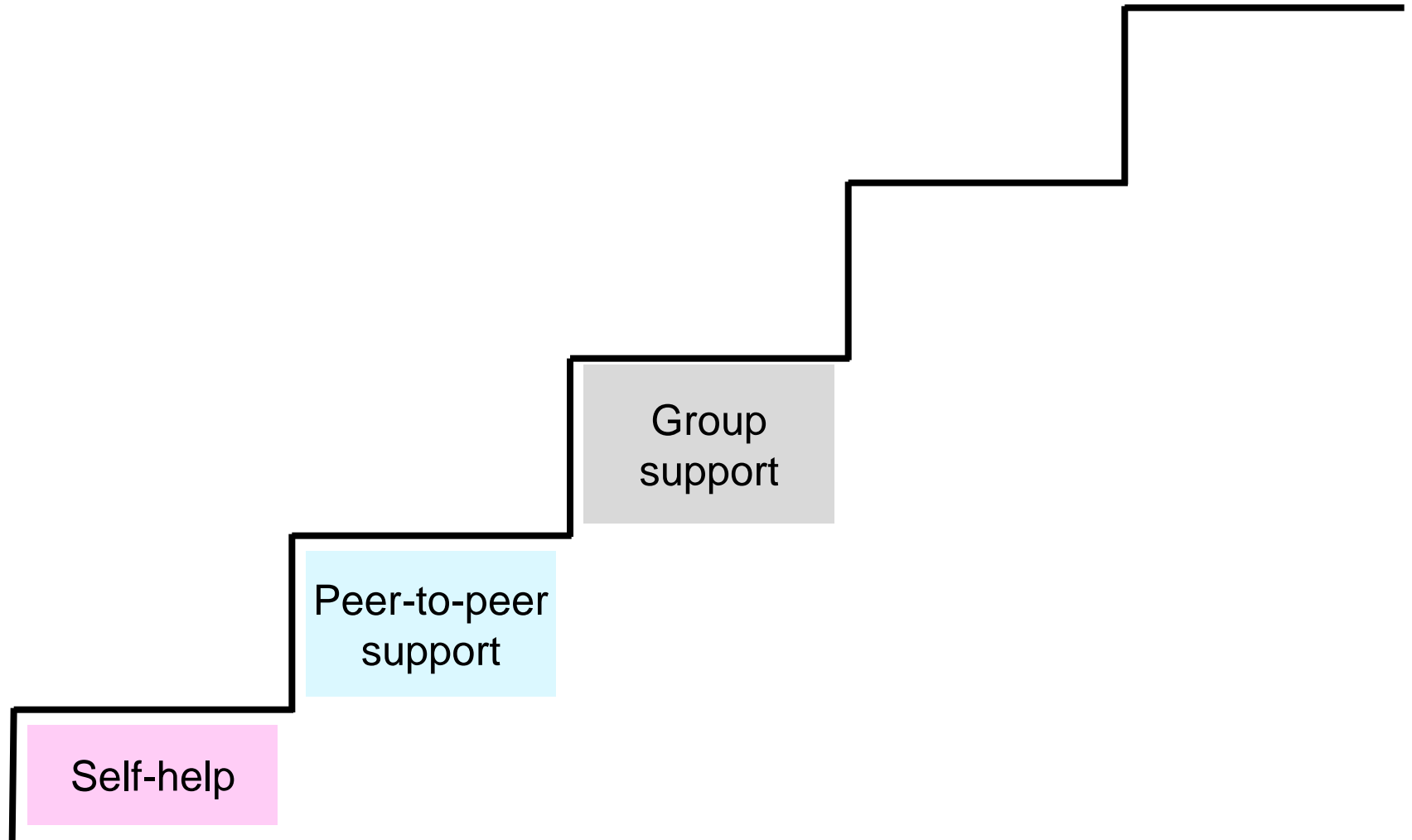
Forum	Stats	Last Post Info
 <b>Loss of a Parent (Mother or Father)</b> Grief support groups for coping with loss of a parent, online bereavement forums offering help with grieving the death of a mother or father.	278 Topics 6,890 Replies	→ Today, 02:19 PM <b>In:</b> Wish you were here <b>By:</b> ModKonnie
 <b>Loss of a Child</b> Grief support groups for coping with loss of a child, online bereavement forums offering help with grieving the death of children, son or daughter.	354 Topics 39,834 Replies	→ Today, 02:28 PM <b>In:</b> I don't think I can do ... <b>By:</b> ModKonnie
 <b>Loss of a Partner</b> Grief support groups for coping with loss of a partner, online bereavement forums offering help with grieving the death of a partner, husband, wife or spouse.	156 Topics 12,255 Replies	→ Today, 05:10 AM <b>In:</b> I Miss Him So... <b>By:</b> fourleafclover
 <b>Losing Family and Friends</b> Grief support groups for coping with loss of a family & friends, online bereavement forums offering help with grieving the death of a friend or family member.	36 Topics 330 Replies	→ 23 March 2011 - 06:22 AM <b>In:</b> lost: grandma, sweet cat, c... <b>By:</b> ModKonnie




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# The staircase of support



# Filling gaps, together...



## Share The Care™

How to Organize A Group to Care for Someone Who Is Seriously Ill

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- THE MODEL
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- ABOUT YOUR GROUP
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- SHARE YOUR ADVICE
- RESOURCES
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**ATTENTION**

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HONORING  
FAMILY  
CAREGIVERS –  
SIGN THE  
PETITION  
TODAY!

*This model is for you if...*

You've never been a caregiver.  
Someone you love has a serious illness.  
They turn to you.  
You don't know what to do.

You've been taking care of someone  
seriously ill for a long time.  
You're burning out.  
You can't do it alone anymore.

REVISED AND UPDATED

Share  
The Care

How to Organize a Group to Care  
for Someone Who Is Seriously Ill

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LIBRARY JOURNAL'S  
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OF THE YEAR

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the  
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**ShareTheCaregiving™, Inc.**  
recently hibernated its 501c3  
to go under the fiscal  
umbrella of the National  
Center for Civic Innovation.  
(see ABOUT THE  
ORGANIZATION). We  
remain dedicated to  
educating the public, health

# How about prescribing this to families?

You are here: [Carers Direct](#) / [Carers' lives](#) / Carers' updates

## Carers' updates

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Carers' updates

### New to Carers Direct?

Carers Direct is the official website designed to help you get the help and support you need as a carer. We offer all the information you should need to get the financial help you're entitled to, as well as advice on getting a break from caring, going to work and much more.



To get you started, why not try our [interactive carer self-assessment quiz](#)? This quiz will take you through just six questions and give you some practical tips on how to get started.

If you don't fancy that, you can start reading whichever section of the site you think will help you. These sections are:



#### Call Carers Direct on 0808 802 0202

Free, confidential information and advice for carers.

Lines are open 8am to 9pm Monday to Friday, 11am to 4pm at weekends. Calls are free from UK landlines and mobiles or you can request a free [call back](#).

You can also ask for a call back in one of more than [170 languages](#) including [العربية](#), [فارسی](#), [中文](#), [Français](#), [हिन्दी](#), [Polski](#), [Português](#), [සිංහල](#), [Soomaali](#), [Español](#), [Türkçe](#) and [اردو](#).

You can send a query to our advisers [by email](#).

Find out more about the [Carers Direct helpline](#).



#### Services near you

Find addresses, phone number and websites for services for carers near you.

# Thousands of youth eager to help...

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youth for health

wellness minds food

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**Beat the Crap Out of Cancer**  
Yi-Min C

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Canadian Cancer Society  
www.cancer.ca  
Let's Make Cancer History | 1

**Joining together in the fight against cancer**

**Welcome to Youth4Health!**  
Check out this page for info on food, wellness and mental health issues. MORE

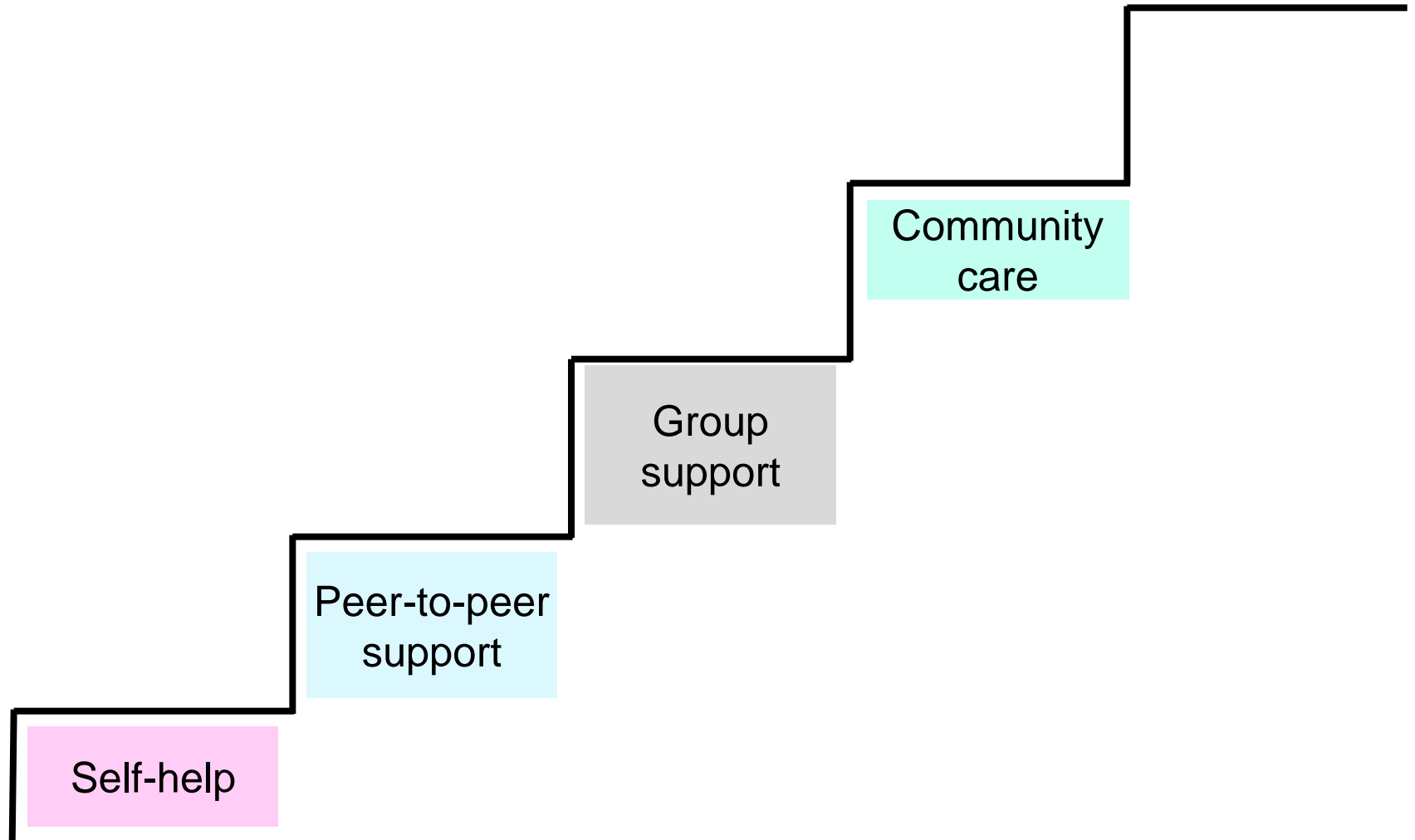
**Need help right now?**  
Call to speak to a counsellor **1-800-668-6868**

**Click here for web resources**

**1 800 668 6868**  
KidsHelpPhone.ca  
Kids Help Phone

**Y4h**  
youth for health

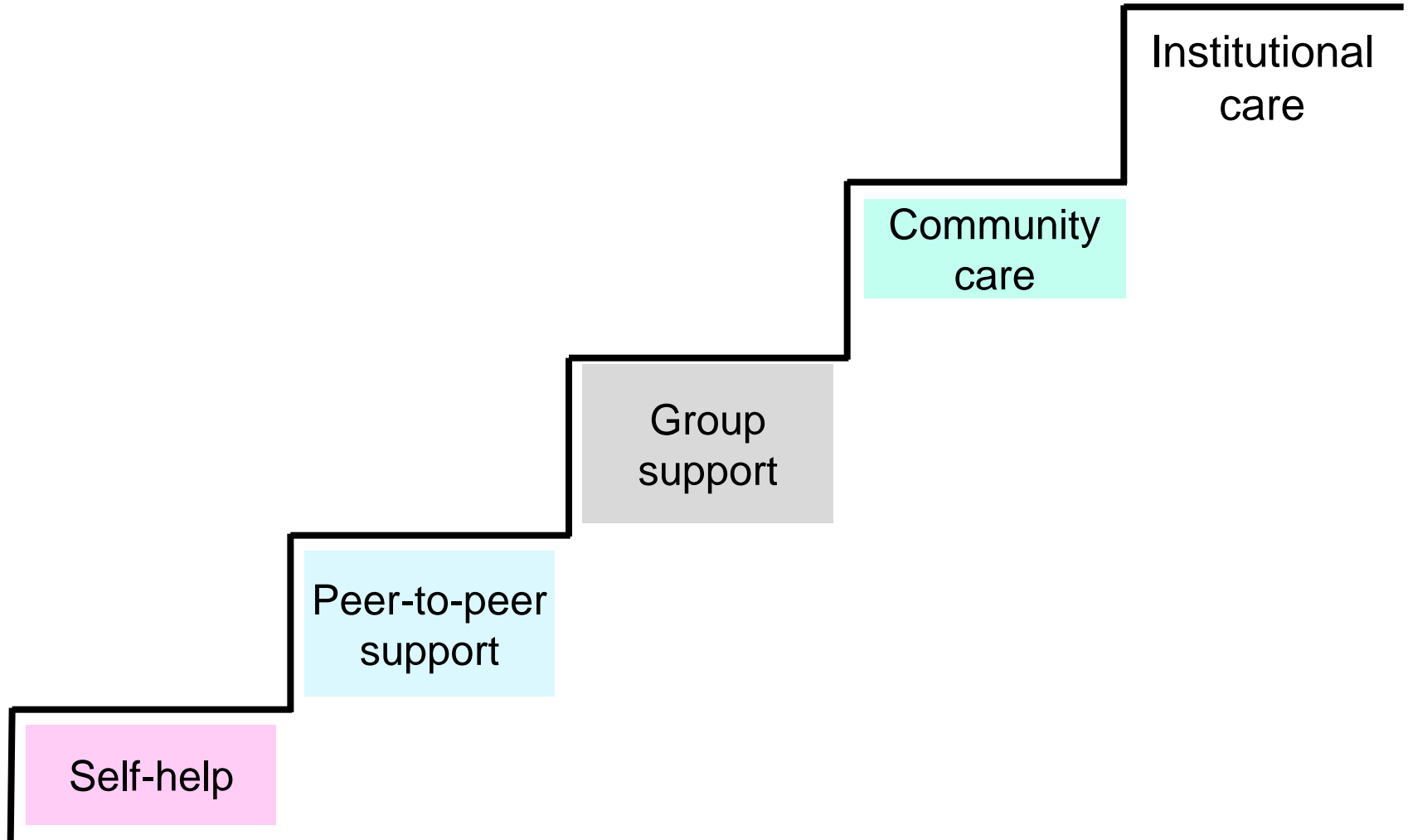
# The staircase of support



# Transforming primary care with free tools



# The staircase of support



# Hospitals as the last resort



# To protect our essence...



“To cure sometimes,  
to alleviate often,  
to console always”

**Unknown origin**

[attributed to Hippocrates, Paré,  
Nightingale, Trudeau, and many others]

# New challenges...



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## Sky Television screens the suicide of a 59 year old Motor Neurone disease sufferer Craig Ewert



★★★★★ 474 ratings

249,294 views

# What should our role be?

Story Tools

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## Healthy Vancouver woman wants to die beside her ailing husband

BY TOM BLACKWELL, NATIONAL POST   APRIL 14, 2009



# Their lives... open to anyone to edit!



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[Read a letter](#) from Jimmy Wales and Michael Snow.

## Betty and George Coumbias

From Wikipedia, the free encyclopedia

**Betty and George Coumbias** are a Canadian married couple seeking to become the first husband and wife to complete simultaneous [suicides](#) with legal authorization. They were featured in John Zaritsky's 2007 documentary, *The Suicide Tourist*.<sup>[1][2]</sup> Although assisted suicide is illegal in [Canada](#), they are hoping to end their lives with the approval of the government of [Switzerland](#).

The couple's request is unusual in that, while George Coumbias suffers from heart disease, Betty Coumbias is reported to be in excellent health.<sup>[3][4]</sup>

Ludwig Minelli, director of Swiss assisted-suicide group [Dignitas](#), has petitioned the [Canton of Zurich](#) to grant doctors the authority to issue lethal drugs to healthy people, after they have been counseled by his organization, hoping to facilitate the Coumbias' suicide pact.<sup>[5][6]</sup>


# Who is studying this?

## News

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## BBC conductor Sir Edward Downes and wife commit suicide

Robert Mendick and Kiran  
Randhawa  
14 Jul 2009

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Maestro: Sir Edward Downes, who gave many Prokofiev performances, is seen with the composer's grand-daughter Anastasia. His wife, with whom he committed suicide, requested the picture be taken

**The son of conductor Sir Edward Downes told today how he and his sister wept as they watched their parents die hand-in-hand at the Dignitas clinic in [Switzerland](#).**

# Preventive suicide?

## British woman kills herself at Swiss suicide clinic to avoid 'prolonged dwindling' of old age

By [DAILY MAIL REPORTER](#)

Last updated at 12:13 PM on 3rd April 2011

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A euthanasia campaigner who dedicated her life to helping the elderly live out their winter years in comfort has killed herself by assisted suicide.

[Nan Maitland](#), founder of the Society for Old Age Rational Suicide (SOARS) which campaigns for a law change over doctor-assisted death, travelled to a Swiss suicide clinic in February. She died on March 1.

The 84-year-old had long been suffering from crippling arthritis and in a moving letter to friends said she chose to escape the 'long period of decline, sometimes called "prolonged dwindling", that so many people unfortunately experience before they die'.

In the note, printed in the Sunday Times, she added: 'For some time, my life has consisted of more pain than pleasure and, over the next months and years the pain will become more and the pleasure less. I have a great feeling of relief that I will have no further need to struggle through each day in dread of what further horrors may lie in wait.'

Ms Maitland is survived by three children, whom she brought up in Kent before moving to London 40 years ago, and a sister.

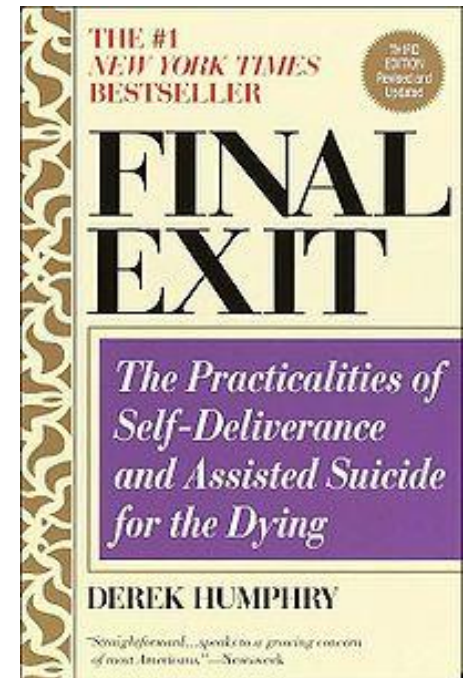
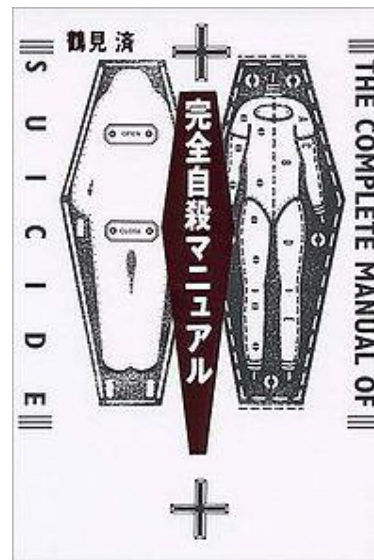
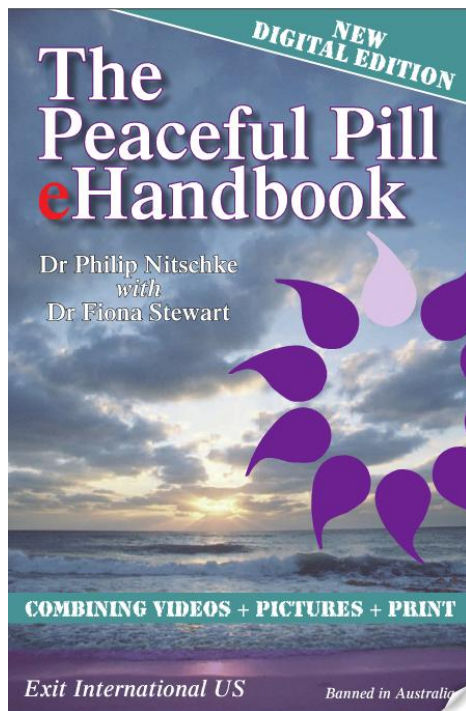


© Crispin Hughes

**Choice:** Nan Maitland had long been suffering from crippling arthritis before choosing to end her life in a Swiss clinic

We are not prepared for this...

EUTHANASIA.com



Suicide Tools by Doghood and worthless

# What is our role here?

Home > News > Story

## Parents Refusing to Remove 'Brain Dead' Baby From Life Support

Moe and Sana Maraachli refused to sign consent when Canadian health officials determined their son Joseph should be removed from life support.

1 2 [next](#) | [single page](#)



13-month-old Joseph Maraachli (CNN)

CNN

1:44 p.m. PST, February 25, 2011

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ONTARIO, BC -- A Canadian family fighting to keep their 13-month-old son on a breathing tube says they have been denied a request to have him transferred to a hospital in Michigan.

# Massive outpour of social support...



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## Baby Joseph NOT in vegetative state

[sjalsevac](#)

8 videos

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0:02 / 0:55 360p

Like Add to Share Embed Download As : 31,614

Uploaded by [sjalsevac](#) on Feb 24, 2011

These two brief videos taken soon before Baby Joseph was scheduled to

47 likes, 2 dislikes

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# A cyber-attack?

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marthagarcia12@gmail.com

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“Monday at 10 am they will kill my baby,” Moe Maraachli, Joseph’s father, told LifeSiteNews shortly after the ruling. “There’s no more humanity. There’s no more chance. I’ve tried everything for him. No more appeals, nothing.”

I am not affiliated with the family of baby Joseph but I think what the Canadian Government is doing to this little baby and his family is horrific! Let's raise a cry throughout facebook! Stand in solidarity with the Maraachli family and proclaim, "Save Baby Joseph!"

<http://www.lifesitenews.com/news/canadian-death-panels-court-rules-babys-life-support-removed-against-parent>

'Death panels': Canadian court rules baby's life support removed against parents' wishes

BY PATRICK B. CRAINE

# Canadian Doctors Playing God?

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Uploaded by FoxNewsInsider on Mar 1, 2011

After a bitter legal fight, a Canadian hospital is allowing the family of their dying baby Joseph to go home. The hospital insists on following a court order to remove the breathing tube that keeps the couple's baby boy alive. One woman knows what this family is going through because her 8-year-old daughter is in a vegetative state because of a neurological disease. For more, log onto <http://www.foxnewsinsider.com>.

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# Baby Joseph - Fox News

FrFrankPavone

160 videos

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0:18 / 3:18

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<http://www.PriestsForLife.org>



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# Cyber-updates from the US...



Videos Posted by Br. Paul O'Donnell



# Is it time to expand our scope?

**CultureLab**

Where books, arts and science collide



## How will you cope, living with your avatar?

13:04 4 April 2011

Books

Samantha Murphy, contributor



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# One physical death. How many virtual?

The New York Times

FINDINGS

## 3-D Avatars Could Put You in Two Places at Once



Cade McCall

**FUTURE IS HERE** Through a 3-D avatar, you could always appear awake.

By JOHN TIERNEY

Published: April 11, 2011

# How do we handle virtual life after death?

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## NEWS

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### Virtual life after death



By Peregrine Andrews  
Producer, Radio 4's i-Shrine

**On 20 May 2010 an event known as "Digital Death Day" brought together the businesses of social networking, data management and death care.**

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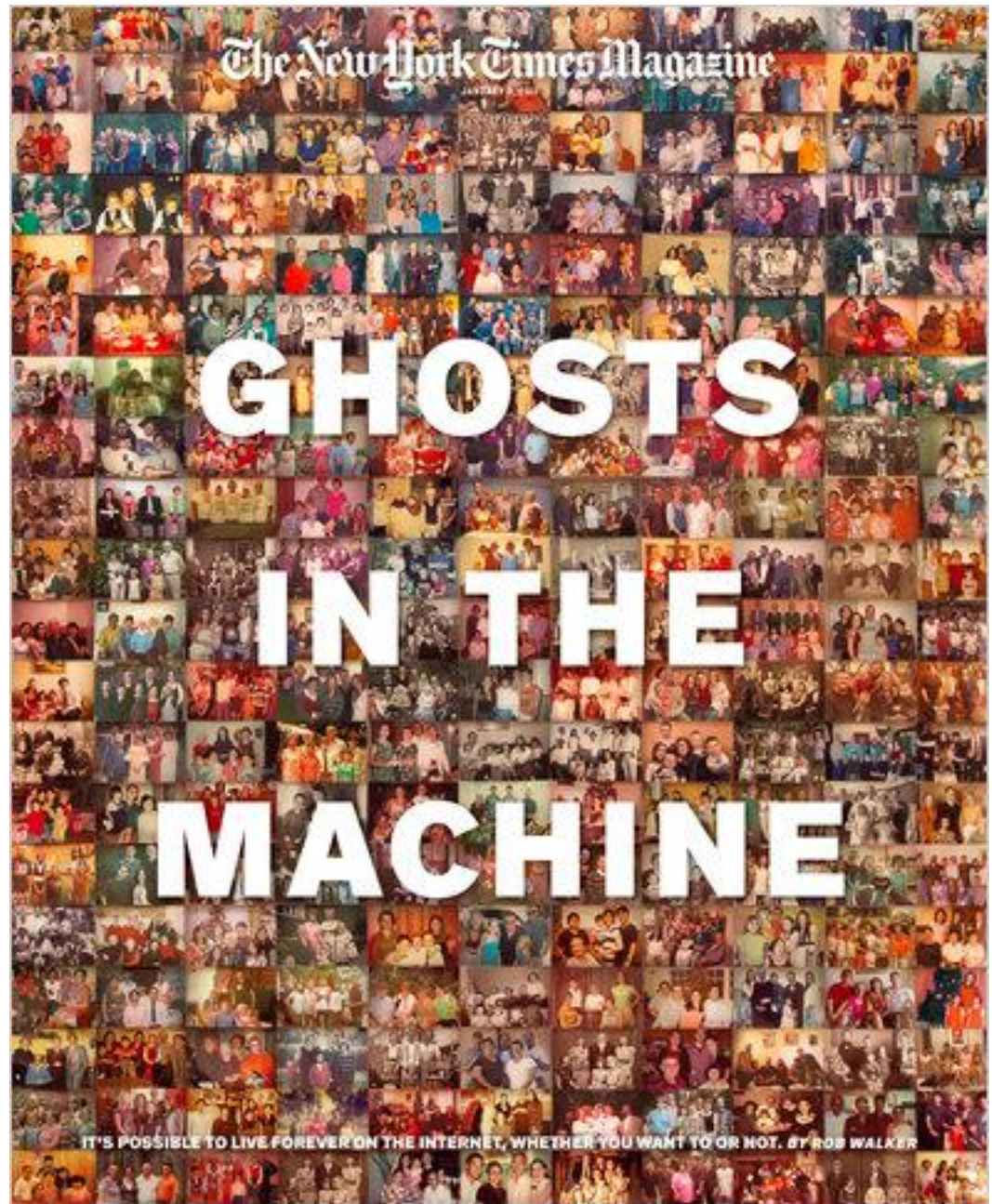
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# Virtual life after death...

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## So what \*does\* happen to your digital assets after you die?

Take a look into the terms of service for various sites like Facebook, Twitter and Gmail.

[→ Read The Article](#)



## Learn more about our new book.

[www.yourdigitalafterlife.com](http://www.yourdigitalafterlife.com)



**News**  
**Digital Death Day**  
**May 6th**

Posted April 9, 2011

It's that time of year again. The second Digital Death Day in North America is coming up May 6th in the San Francisco Bay Area. Are you excited? We definitely are. With all of the attention that the topic has received over the last few months, we're anticipating a great event. John and I will [...] [→ Continue Reading](#)

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**Archival**  
**Archiving Facebook, Twitter and Other Social Media Sites**

Posted March 21, 2011

In our advice about planning your digital legacy, we talk at length about usernames, passwords and wishes. Leaving behind detailed instructions for accessing your online accounts can save your heirs a good deal of frustration. But this approach assumes that the service is still available when your heirs go looking. Moreover, it assumes that you're [...] [→ Continue Reading](#)

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**Digital Death Day 2011**  
May 6, 2011  
[www.digitaldeathday.com](http://www.digitaldeathday.com)

What will happen to your digital possessions after you die?



# Digital Death Day

Welcome

Updates

About

## Welcome



*photo by Tomas Valenzuela Blejer*

\* We are organizing a drinks evening after Friday February 24th.

\* You're Dead, Your Data Isn't: What Happens

\* We have an "officially listed" meetup gathering

If you are a:

\* Funeral Director

\* Thanatologist

\* Social Network Admin

\* Data Systems Admin

\* Product Manager

\* Information Systems Researcher

\* HCI Researcher

\* Digital Designer

\* Psychologist or Grief Counselor

\* Palliative Care Specialist

\* Historian

\* Pre-Need Sales Person

\* Funeral Celebrant

\* Estate Planner

\* Legacy Planner

\* End of Life Planner

\* Solicitors and Barristers in Intellectual Property and Estate Law

\* Clergy

\* Or Simply an Interested Human Being

# How about eTouch?

## The hug shirt helps you feel distant loved ones

By Barb Dybwad  posted April 25th 2005 7:46PM

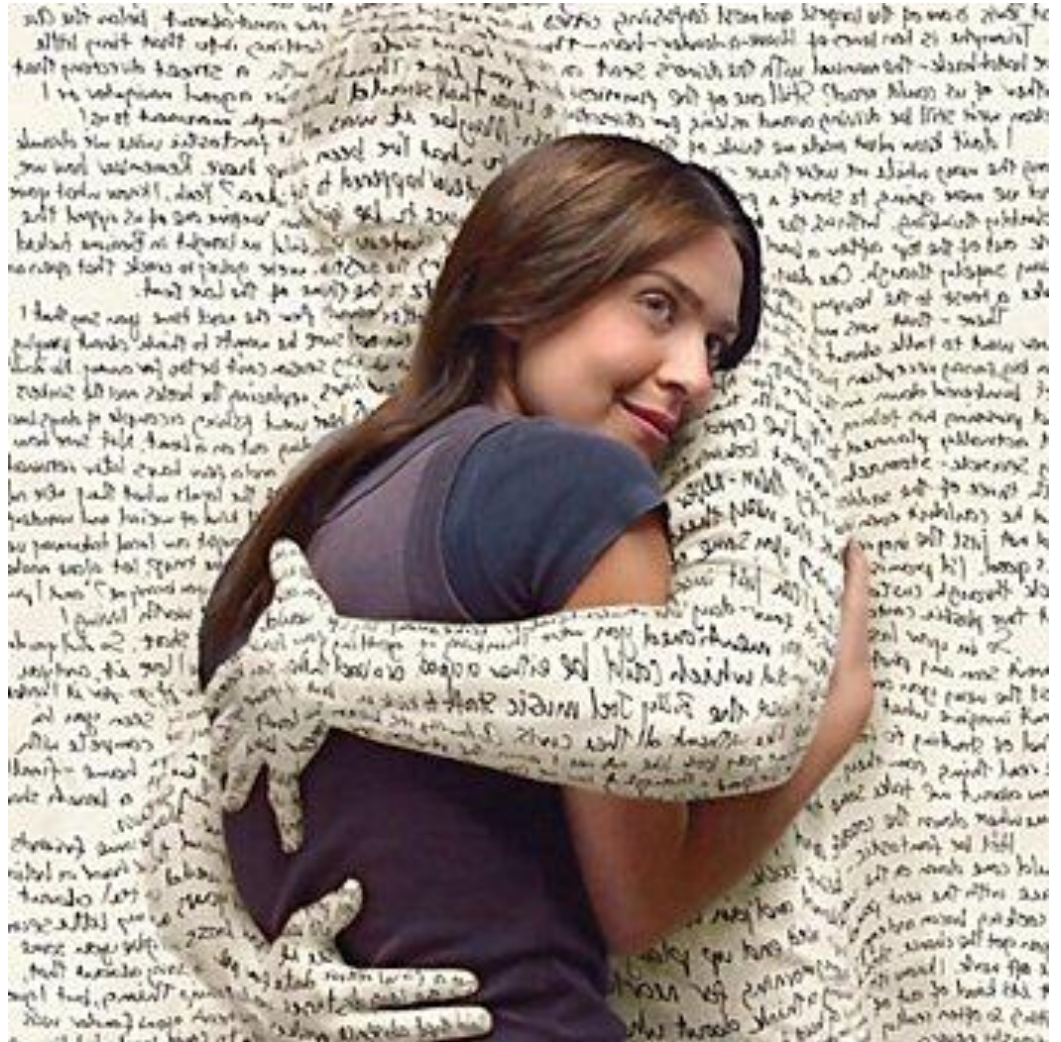


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How could we  
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touch with the  
high tech?



Is it time to re-focus on our healing abilities?



Will we have the courage, fear or generosity  
needed to meet their expectations?



# Thinking Ahead in Palliative Care

Annual Conference 2011

