

Compassionate Communication in the Medical Home

Lessons from Palliative Care

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MA Consortium for Children with Special Health Care Needs

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Medical Home Casserole

preheat practice to 2010°

- **Accessibility**
- **Family-centeredness**
- **Continuity**
- **Comprehensiveness**
- **Coordination**
- **Cultural effectiveness**
- **Compassion**



Compassion

- **Do we take it for granted?**
- **Can we define it?**
- **What gets in the way?**
- **Can it be taught?**

Compassion

- **Do we take it for granted?**

Compassion:

Two reasons we take it for granted

1. We are *all* compassionate
2. We commodify Medical Home
 - Accessible if...ramps & elevators
 - Coordinated if...professional CC
 - Family-centered if...FAC in place
 - Culturally effective if...alguien habla español

Compassion is hard to check off a list

Reason #3:

Compassion is the one element of
Medical Home
that
depends entirely
on provider behavior

Compassion

- **Do we take it for granted?**
- **Can we define it?**

Compassion defined

- Literally, suffering with another; a sensation of sorrow excited by the distress or misfortunes of another; pity; commiseration

Webster's Dictionary 1913

- 1: a deep awareness of and sympathy for another's suffering
- 2: the humane quality of understanding the suffering of others and wanting to do something about it [syn: pity]

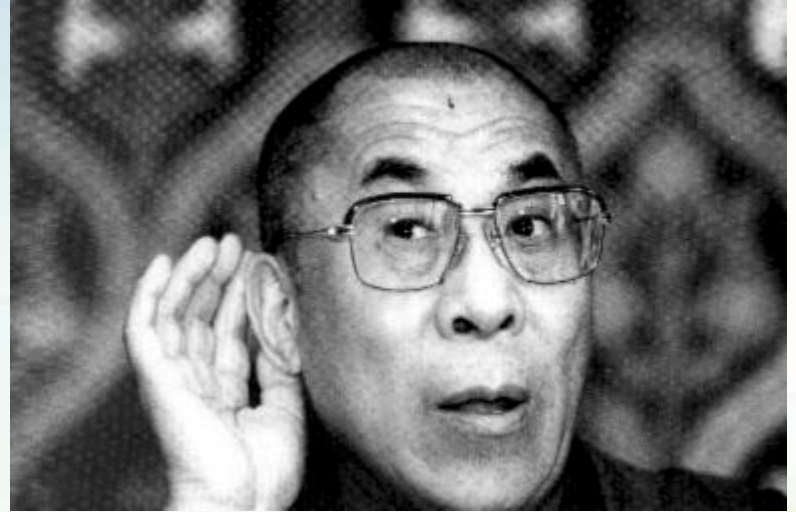
American Heritage Dictionary

Question of the Day: what is compassion in Medical Home?

→ *Index cards*

some opinions › › ›

H.H. the Dalai Lama



- **If you want others to be happy, practice compassion.**
- **If you want to be happy, yourself, practice compassion.**

Gary Zukav



•Without an awareness of our feelings we cannot experience compassion. How can we share the sufferings and the joys of others if we cannot experience our own?

Sogyal Rinpoche

- ... we start to have a burning, almost heartbreaking sense of the fragility and preciousness of each moment and each being, and from this can grow a deep, clear, limitless compassion for all beings.

see <http://www.rigpa.org/>



Thomas Merton

The whole idea of compassion is based on a keen awareness of the interdependence of all these living beings...



[http://www.monks.org/
thomasmerton.html](http://www.monks.org/thomasmerton.html)

Joseph Campbell



- **When you have come past all the pairs of opposites you have reached compassion...
*The purpose of the journey is compassion.***

<http://www.jcf.org/>

Deep...



and by the way...

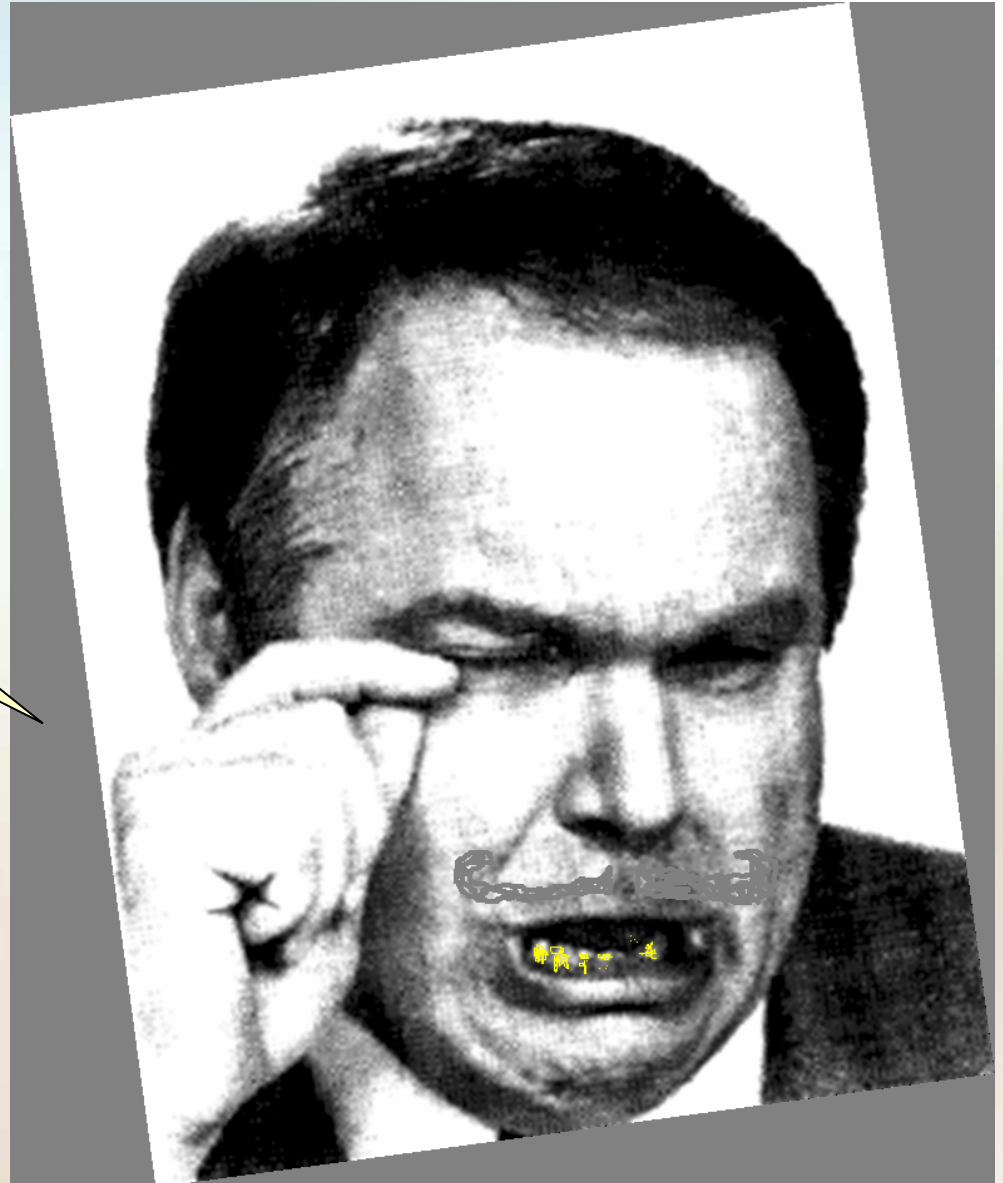
**It's OK to remain a
radical atheist...
the important thing is
a compassionate heart
—then, no problem.**



Rush Limbaugh

Compassion is
no substitute for
justice

www.oxycontin.com



Resources on Pediatric Palliative Care & Compassionate Care

- **<http://www.medicalhomeinfo.org/index.html>**



AAHP definition

- **... comprehensive, specialized care provided by an interdisciplinary team to patients and families living with a life-threatening or severe advanced illness expected to progress toward dying and where care is particularly focused on alleviating suffering and promoting quality of life.**

American Academy of Hospice and Palliative Medicine

AAP Recommendations

- provide support and anticipatory guidance for children and families who face death
- encourage open discussion of reactions, thoughts, and feelings in the family ... increasing the sense of mutual support and cohesion
- positive outcomes associated with:
 - age-appropriate and culturally sensitive guidance
 - ability to share
 - reliance on family members
 - good communication

AAP Committee on Psychosocial Aspects of Child and Family Health, The Pediatrician and Childhood Bereavement. *Pediatrics*. 2000;105(2):445-447

Palliative Care in the Medical Home

- combines palliative and life-prolonging care
- part of the general philosophy of care, not a separate part or place
- concern for child/youth and family is demonstrated in verbal and nonverbal interactions
- efforts made to understand and empathize with the feelings and perspectives of the family as well as the child or youth

AAP Committee on Bioethics and Committee on Hospital Care. Palliative Care for Children. *Pediatrics* Volume 106, Number 02 August 2000, pp 351-357

Compassion

- **Do we take it for granted?**
- **Can we define it?**
- **What gets in the way?**



**Our culture denies the fact
that children *do* die**

<http://www.pediatrics.org/cgi/content/full/115/1/57>

injustice of death in childhood



deep emotional responses



behaviors that *reinforce denial* and

prohibit productive dialogue and action

Standards alone insufficient

Focus on

- attitudes
- beliefs
- training

of pediatric professionals

- Himmelstein BP, Hilden JM, Boldt AM, Weissman D. Pediatric Palliative Care - Medical Progress. N Engl J Med. 2004; 351:301-302

**Compassion is the one element of
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Compassion

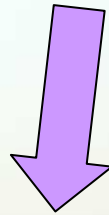
- **Do we take it for granted?**
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A photograph of a weathered wooden sign nailed to a tree trunk. The sign is rectangular and has a mottled, aged appearance with shades of brown and tan. It is attached to a thick, dark brown tree trunk with rough, textured bark. The background shows out-of-focus green foliage and a hint of a building. The entire image is framed by a solid blue border.

the
kingdom
is now
or never

Explicit recognition that the work
has an element of emotional labor

Conscious acts to empathize with
patients



- **more effective healers**
- **more professional satisfaction**
 - Clinical Empathy as Emotional Labor in the Patient-Physician Relationship Eric B. Larson, MD, MPH; Xin Yao, PhC
JAMA. 2005;293:1100-1106

How different are our feelings about
kids born with chronic conditions?



The Medical Home Connection

- **CSHCN aren't necessarily kids with advanced illness**
- **Difficult conversations**
- **Making hard choices together***

***See Cameron Lord story**

http://www.carepoints.org/auxilium/cms/view_now.asp?objectid=1359

Circumventing Common Communication Cock-ups #1



When using the telephone for news



Try this....



- *Come in*
- *Bring a friend*
- *Make a plan*

courtesy Matt Sadof, MD

Another way to use the phone

- The “no reason” call
- *I wanted to see how you were getting along*

if you're wondering...
is this too much for them?

- **Suggest a resource**
 - *It might be helpful to speak with...*
- **Be a resource**
 - *Would it help you if I spoke with your parents?*

Greatest resources you have

- **unconditional positive regard**
- **respect**
- **receptivity, authentic openness**
 - *affective*
 - *cognitive*
 - *relational*

Pediatrician has unique capacity...

- **To hear**
- **To understand**
- **To recognize**
- **To say:**

I know where you are.

We will get through this together.



Will it make a difference?

- **Your investment of self conveys confidence in family's capacity**
 - *to grow*
 - *to evolve*
 - *to master*
- **You have more to offer than you know**

and because.....

• *See **Beyond Empathy: A Therapy of Contact-in-Relationship** by Richard G. Erskine,*
www.integrativetherapy.com/article-empathy.html



not a zero-sum game

Give one heart

Get back two

Thich Nhat Hanh



•The amount of freedom you have can be measured by the amount of understanding and compassion you have in your heart.

see www.plumvillage.org