AHC Media

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CHRONIC CONDITIONS

WHAT WE NEED TO KNOW TO HELP

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SPEAKER

Karen Zander, RN, MS, CMAC FAAN

Zander is president and CEO of The Center for Case Management. Her pioneering work with clinical case management and CareMap systems, begun at New England Medical Center Hospitals in Boston almost 30 years ago, is internationally recognized. She is the author of many articles and books about case management and editor of *The New Definition* newsletter. Zander earned a BSN from Illinois Wesleyan University, an MS in Psychiatric-Mental Health Nursing from Boston University, post-graduate credits from MIT, and a Doctorate in Humane Letters, honoris causa, from Ill. Wesleyan University

OBJECTIVES

1. Explain how chronic conditions and illnesses impact patients and their families.
2. Evaluate the current national goal of keeping people at their highest level of functioning and wellness.
3. Describe the impact of personal patient stories in providing patient care.
4. Discuss issues that impact healthcare protocols and practices.

EVERYONE HAS (AT LEAST ONE) SOMETHING!

- Prone-ness, like cavities, lazy eye, acne, posture
- Worrying about genetics, like bi-polar
- Allergies
- Sleep disturbances
- Aches and Pains in same locations
- Migraines, Gastric Reflux
- Side-effects of Medications
- Crohn's Disease, IBS, Asthma, HepC, Cystic Fibrosis
- Brain Injury, Chronic Kidney Disease, Parkinson's, Autism spectrum
- Aging

ABOUT GETTING OLDER –

- "I think it's like a lot of things about getting older — you have absolutely no imagination that this is actually going to happen to you," she told NPR's Neal Conan several years ago. "You think for quite a while you're going to be the only person who doesn't need reading glasses, or the only person who doesn't go through menopause ... and in the end, the only person who isn't going to die. And then you suddenly are faced with whichever of those things it is, and you can't believe how unimaginative you have been about what it actually consists of." N. Ephron

NEW: ABOUT AGING

"Most research assumes that chronic diseases arise and should be treated individually. What if, instead, aging is the root cause of many chronic diseases, and aging can be slowed?"

Source: Gregg Easterbrook, The Atlantic, Sept 17, 2014.

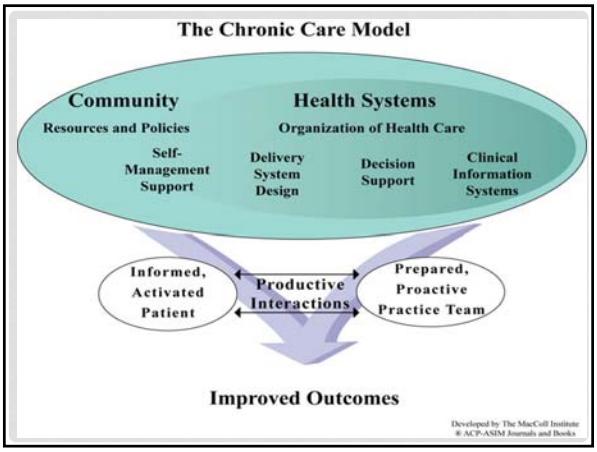
CAUSES OF ILL HEALTH

POLL BY RWJ FOUNDATION, NPR, HARVARD SCHOOL PUBLIC HEALTH
WWW.WBUR.ORG MARCH 2, 2015

9% Bad Luck
19% Bad Genes
27% Low Income
29% God's Will
31% Not enough education
33% Being Abused as an adult

DEFINITIONS

- **Chronic = Severe and Persistent; "the long haul"; "like a Home Invasion!"** (from MLSheehan, RN, MS)
- **Disease = Pathophysiologic change** (Lubkin and Larsen, p. 4)
- **Illness = Personal response to disease** (Lubkin and Larsen, p. 4)
- **Condition = A set of signs, symptoms, and problems caused by the chronic disease that require continuous monitoring and problem-solving to stay well** (Zander, 2012)
- **Complexly Ill = those patients with interacting biopsychological and health system barriers to improvement, including mental and substance use disorders, inadequate social networks, limited, poorly-coordinated access to need health services.** (Kathol, Perez, Cohen)
- **Population Health = Focus of interventions on homogeneously-defined patient group.**



ROLES: HELP OTHERS GET AND STAY AT THEIR HIGHEST LEVEL OF WELLNESS

- Health care professional
- Embedded Case Managers with PCPs
- Wellness coach
- Navigator
- Health/Care Guide
- Transition Specialists
- Disease management program
- Concerned family member
- Friends, Influencers
- Jenny Craig, Weight Watchers, AA, etc.

CARE COORDINATION FOR CHRONIC ILLNESS/CONDITIONS: CENTRAL TO FUTURE OF HEALTHCARE

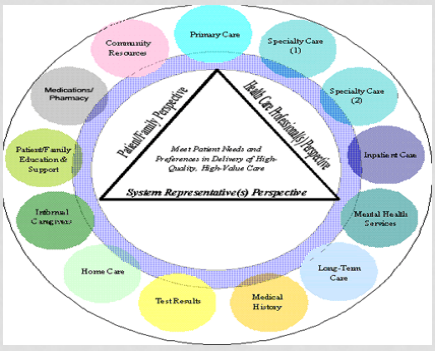
- **"Care Coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services.**
- **Organizing care involves the marshaling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for the different aspects of care."**

Three Perspectives/Measures

1. The Patient and Family
2. The Professionals
3. The System

Source: AHRQ Pub #11-0023-EF; Care Coordination Measures Atlas; December 2010, p.4

AHRQ: CARE COORDINATION 2010



CMSA RECOMMENDED CASELOAD FOR HIGHLY COMPLEX PTS

"The caseload for integrated case managers should not exceed one manager to 70 active complex cases. In public programs where health complexity is usually higher, the number of patients serviced per case managers should be no more than 1:20."

Range 1:30-50.

Highly complex patients average 3-6 months with a case manager

1 integrated case manager can serve 60-200 patients/year.

(Source: Kathol and Perez, p. 35.)

PPACA AND CHRONIC DISEASE MANAGEMENT

The Patient Protection and Affordable Care Act (2010) refers to chronic disease management as an "Essential Health Benefit" that must be covered.

Chronic Disease Management Programs are classified as Quality Initiatives under the medical loss ratio guidelines (MLR) vs. traditional UR, which is classified as Administrative, which must only require 15-20% of premiums.

"…we should expect to see them continue to proliferate" Source: Levitt, C. (June, 2012) Healthcare lingo: let's get on the same page", Case in Point, p.20

CORE COMPETENCY OF CARE COORDINATION IS LATERAL LEADERSHIP: LEADING WHEN YOU'RE NOT IN CHARGE*

Case Managers provide decision support and problem-solving through the act of pulling others into an activity or goal. (Zander)

*Source: Fisher, R and Sharp, A. Getting It Done, HarperPerennial, 1998.

THE BASIC QUESTIONS FOR EVERY CASE MANAGER-IP OR OP

- Is there a real team, an ad hoc team, or no team?
- If no, how do you make a team when no one wants to play?
- Is there care/treatment planning going on?
- If yes, how can case managers and social workers participate?
- If no, how can you engage an entire organization?
- When do case managers have to take authority and ownership because no one else will?
- What are the paths to ownership?

CORE COMPETENCY: ASSESSING LEVEL OF PATIENT/FAMILY ABILITY

1. Compliance: Strictly following medical advice

2. Adherence: Adjusting medical advice on a situational basis

3. Self-management: Understanding mind and body so well that medical advice sought only for specific reasons

Source: Hamilton, G. Increasing adherence in patients with primary hypertension: An intervention.
Hamilton, Glenys A.; Roberts, Susan J.; Johnson, Johanna M.; Tropp, Jessica R.; et al
Health Values: The Journal of Health Behavior, Education & Promotion, Vol. 17(1), Jan-Feb 1993, 3-11.

SELF-MANAGEMENT

- Managing chronic conditions boils down to managing symptoms and risks
- Self-managing people manage other people's knowledge, commitment, involvement, care of them, and reactions
- Self-managing people build networks, need someone to care about them, and sometimes need anti-depressants
- Case Example: Taxi driver in Charleston, SC.

CORE COMPETENCY: INSIDER EXPERT

1. BONDING: Becoming known, believing you have their best interests at heart
2. Working: Helping the patient think differently to redefine self and situation
3. Changing: Trying new ways

Source: Lamb and Stempel, "Nurse Case Management from the Client's View: Growing as Insider Expert", Nursing Outlook (42) No 1, Jan/Feb, 1994.

CHRONICITY STRIKES THE FAMILY TOO

- Family is finally being acknowledged
- Not just a "necessary evil," annoyance, anymore
- Patient **AND** Family
- Now a partner, not an accessory

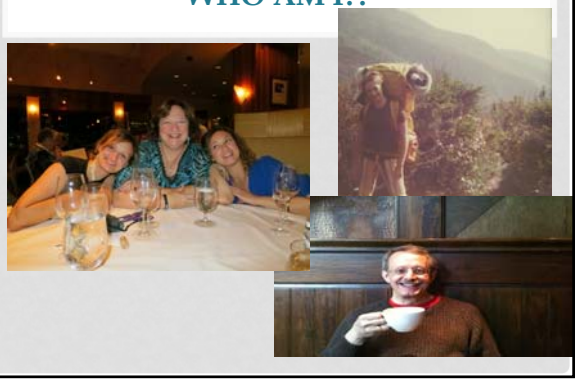
CORE COMPETENCY: MEANINGS OF ILLNESS AND CHRONIC CONDITIONS

- Loss
- Punishment
- Reward
- Challenge
- Relief
- Other?

- 1953 Transverse Myelitis secondary to Broken Arm
- 1 year therapy
- 50 years fine
- 2000: symptoms, many MDs
- Chiropractor
- MRI : DX: 2005 syrinx and tethered spinal cord
- 2006: Consults with renown MDs
- SCI T 4-6 October 7, 2007
- October 9, 2007

MY "STORY" AND TIMELINE

WHO AM I??



MAIN ISSUES: LOSS AND FEAR

(SOURCE: J. JACKSON, MSW; PRESIDENT, ELDERCARE ADVISORS)

"The goal is NOT acceptance [or coping/adapting] but **acknowledgement**"

MORE THEMES

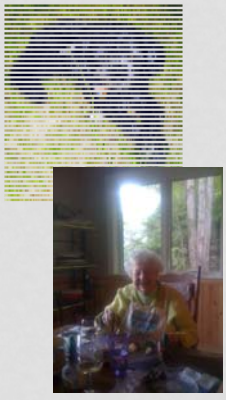
It is not the fear of dying that bothers people, but the fear of:

- Not being able to stay in one's own home
- Fear of being a burden
- Fear of running out of money

Source: J. Jackson

1. Extension of SCI
2. Lungs
3. Skin
4. Weight/ Diabetes
5. Guess what?

TOP 5 FEARS... STILL!



MY SURPRISE LOSSES:

STAMINA
PROPRIOCEPTION
EFFICIENCY
PRIVACY
MY HOUSE
MY SUITS
OUR DOG
HUGGING MY MOTHER
PRIVACY
MY FUTURE:
GRANDCHILDREN
SEE 7 CONTINENTS

- "Each person recovers from loss at a different pace. We react according to who we are, our histories, and our present circumstances."
- "When well-meaning people push us to 'move on', to 'put behind us'; to 'get a grip', or to 'try to forget about it', its often because they don't know how to tolerate or respond to our state of mind."

WE CAN'T GET OVER A LOSS: WE CAN ONLY GET THROUGH IT.

COGNOSCENTI.WBUR.ORG/2014/04/08

MENTAL CONDITION CO-MORBIDITY

Condition	Prevalence
Neurological	37.5%
Heart disease	34.6%
COPD	30.9%
Cancer	30.3%
Arthritis	25.3%
Diabetes	25%
Hypertension	22.4%

Source: Melek, S., from Milliman Healthcare Symposium, March 2008

- Dil is not a pickle and the Bowel Program is not a Broadway Show
- Gas is not what you heat with
- Core is not in an apple, and do I ever miss it!
- Tipper Bar is not a place to get drunk
- Gimp is not what you used for crafts at summer camp
- AD does not stand for Ano Domini=Autonomic Dysreflexia
- SexEd—what part is sex?

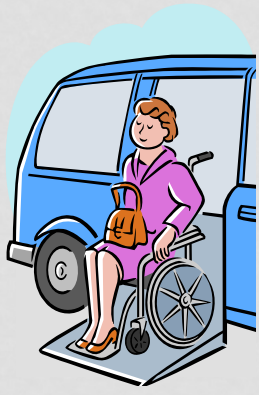
REHAB "EDUCATION"

- Private Case Manager
- Sheraton Needham
- It's all about the bathroom…
- Private-pay Home Care
- Spaulding OP

COMING "HOME"

MINDSHIFT:

CONVERTED DEPENDENCY TO TRUST *IN SPECIFIC PEOPLE ABOUT AUTOMATIC PROCEDURES;* OTHERWISE, NEVER LET DOWN YOUR GUARD.



YEAR 1:
LEARNED TO DRIVE
WROTE CM MODELS BOOK
PLANNED REPLACEMENT
LAKEHOUSE
STARTED LAW SUIT
BERNIE LEARNED HOW TO REPAIR WHEELCHAIRS
FIGURED OUT HOW TO TRAVEL
SPENT $$$$$$$$$$$$$$

BEING THE "GOOD" PATIENT?

"I think there is danger when researchers think there is a right way to have a chronic illness. There is only one way…the one you choose at the moment. Generally, I live in the orange. If red is illness and yellow represents wellness, then I like to be a blend of both things…in the orange.

It is not a good idea for me to be completely yellow because then I forget that I have MS and I do stupid things that I pay for later. And if I am totally in the red, I am too depressed to do anything."

(Paterson, 2003, p.990 in Lubkin and Larsen)

MY OWN 5+RULES FOR "LIVING IN THE ORANGE"

- Build and Nurture a "Para-Network"
- Dr. Carter about Standards vs. Priorities
- "I will NOT ADAPT"
- Cymbalta
- Stay informed
- My Reality Goal: Re-walk or Eksoskeleton

RULE #1: KEEP SANE

- Daily Forteo injections
- HHA Schedule requests
- Med refills
- Exercise appts.
- Monthly Catheter changes
- Podiatrist
- Bone scans
- Transfer board to dentist and hair appts
- Van repairs/upkeep
- Wheelchair parts

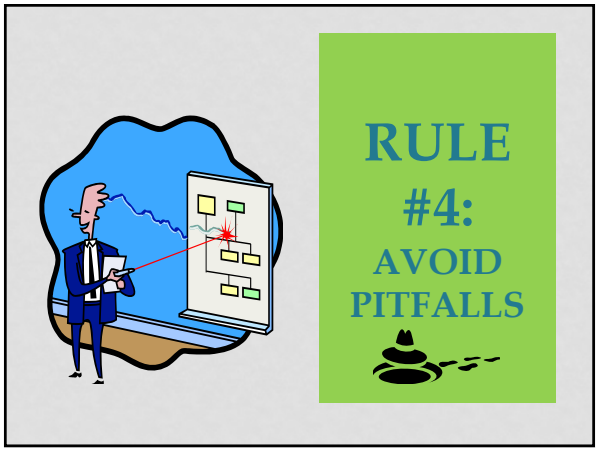
RULE #2:

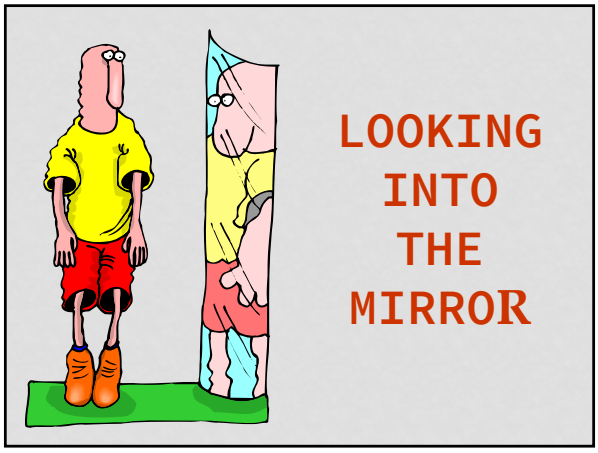
KEEP ORGANIZED WITH A BALANCED SCHEDULE

- Journey Forward, Canton, MA www.Journey_forward.org
- ExPD, Spaulding, Cambridge
- Standing Frame
- Exercise Platform
- Transfer Boards
- Outrigger Canoe Paddling
- Water-Skiing (Northeast Passage-UNH)
- CRI sculling
- Bocce ball
- Cycling Cape Cod Canal
- "It's all you"
- Driving

RULE #3:

KEEP MOVING

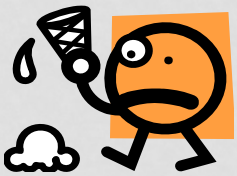

RULE
#4:
AVOID
PITFALLS


LOOKING
INTO
THE
MIRROR

SINKING INTO VICTIMIZATION

EM-
BARE-
ASS
MENT

ANXIETY AND PANIC



FRUSTRATION AND LACK OF PATIENCE

A PERSPECTIVE

" Like dealing with a serious illness [chronic condition], baseball favors the quiet and the patient--people who won't freak out when the count is against them, even though things look bad from the dugout."

Tracy Mayor, Oct 18, 2013, WBUR Cognoscenti

RULE #5: BE GRATEFUL, GIVE PEOPLE A CHANCE TO DO THE "RIGHT" THING

AND KEEP CONNECTED

CONCLUSION: I AM A "RESISTANT ADAPTER"

(LIKE TRAVIS ROY)

PS WHATEVER IT IS, IT IS NOT "THE NEW NORMAL" AND I HATE THE LABEL "RESILIENT"

WORKING WITH CHRONICALLY-ILL PEOPLE

- **"Be kind: for everyone you meet is fighting their battle, too"**
- **Be kind to yourself—this is hard work!**
- **Use data to help you be objective**
- **Be eager to learn from your clients**
- **Keep yourself well and energized!**

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THE END! QUESTIONS?