



















*"Some of them treat me like I'm already dead

*I know I have cancer ... and yes I know my life may be limited...... but I'm living with thisNot dying with it Yet !!!!

*Why do they talk as if we are in a church? I'm not even religious!

*I'm alive !!!! Playing the guitar and listening to the Beatles.....

*I don't want people around me like that"

**Mr Ormrod





- *Every time I go near them ... all I get is ..
- * "Well Mr Ruhe ... just what have you been up to? Your blood glucose is telling us you've been very naughty."
- * I always feel told off
- * How would you feel if someone treated you like that?
- * It just feels hopeless
- *They never ask me what its been like for me?
- * All my whanau have this so why should I think it can be any different for me?
- *I just avoid goingwhy would I bother?





*" It sucks How would you like never to be able to do the things your friends do?" *I hate the endlessness of it ... my parents always checking to see I am doing the right things

*I just want to be normal .. I don't want to be different ... I'm not sick!"

*I don't want this diabetes!



*Mr Knight 16yrs

- *"I was so shocked to be told I had this ... (MS)
- *they seemed to just think it was normal ...that I would not be devastatedmaybe they deal with this every day ... but it felt like my whole life just simply disappeared ...
- *I might as well have had cancer!!!... I didn't hear a thing after that ...



- *He says (the doc) that many people living with these things gets depressed .. It's to be expected .
- *But I hate feeling like this .. I don't expect it and I don't want
- *My mother always taught me to live life and not regret .. How can I live it if I feel like this?
- *Everything is shrinking ... my world is getting smaller .. Soon I will disappear
- *Why can't they help me?



*Mrs Goldbloom, 76

- * Why can't they talk to each other?
- *I just visited my endocrinologist on Monday and he had no idea I had been in hospital with chest pain
- * I'm on a whole bunch of new drugs and now he says not to take them
- * Who do I believe ?
- * Why can they get their ducks in a row?
- * It costs me big time to get to all these damn appointments and it seems I'm the one who has to carry the burden of letting them all know what is happening!
- * Last Monday was 4 hours all up by the time I got there , waited as usual and then got home .. Half a days work
- * All very well for them!

*Mr Brown, 58





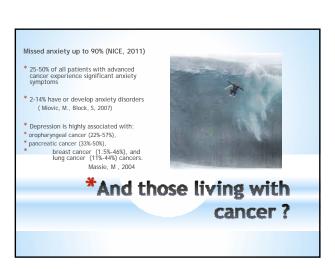












- *During the past month have you been feeling down, depressed or hopeless?
- *During the past month have you been bothered by having little interest or pleasure in doing things?
- *Would you like help with this?



- *If we do not assess, screen and offer support
- * We structure " non concordance"
- *Severely reduce the likelihood of self- management
- *Can cause misery and additional suffering for all
- *Cheat people out of quality of life

*Why is this so crucial

- *Compliant : behaviour matches prescribers advice
- *Adherence : behaviour matches agreed recommendations
- *Concordance: the prescription represents a shared decision in which the beliefs and preferences of the patent have been taken into consideration. Bissell, May, Noyce, 2004, Horne, 2006.

Language Matters ... the power of words

- *This was Orm "living with" cancer
- * "I am not a diabetic .. I happen to be Lizzie who has lived with diabetes for 55 years and done it well"

*Language matters!
They are not their disease or pathology

*What people and their families say they want

- To be listened to, taken seriously, and respected as a care partner
 - To have my family/caregivers treated the same
 To participate in decision making at the level I choose
- To be always told the truth
 - To have things explained to me fully and clearly
 To receive an explanation and apology if things
 go wrong

- To have information communicated to all my care team
 - To have my care documented promptly and accurately To have these records made available to me if requested
- To have coordination among all members of the health care team across settings
- To be supported emotionally as well as physically
- To receive high-quality, safe care

 $\frac{http://www.ini.org/lHJ/Topics/PatientCenteredCare/PatientCenteredCareGeneral/ImprovementStories/DeliveringGreatCareEngagingPatientSandFamiliesasPartners.htm$



Why Do We Need To Change? *Disease burden has changed towards long-term conditions around the world. Health systems have not. *Effective interventions exist for most long-term conditions, yet patients/clients do not receive them. *Current health systems are designed to provide episodic, acute health care and fail to address self-management, prevention and follow up.

WHO Health Care for Chronic Conditions team (CCH) http://w hqlibdoc.who.int/hq/2002/WHO_NMC_CCH_02.01.pdf

*People living with long-term conditions require a different kind of health care (mismatch).

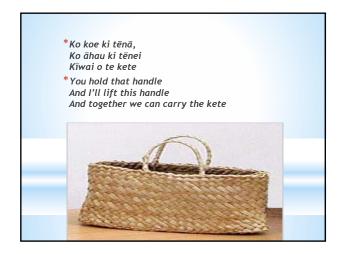
Triple Aim Primary Care??

- What we have
 - Visit based/ brief "encounters"
 - Usually built around needs of practice and providers
 - Historical craft based roles; often working in silos
 - Rigid clinician visit centric payment model/ limited flexibility
 - Medically resourced

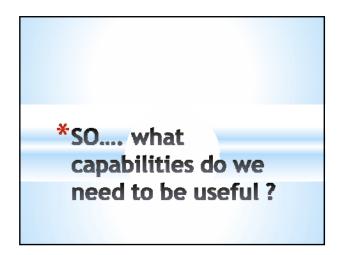
- What we need
 - Population focused/ "continuous relationships"
 - Built around/ responsive to needs of patient/ community
 - Team "community of
 - Empowered for continuous learning with resources, skills, aligned incentives
 - Resourced to population needs/ integrative with the community

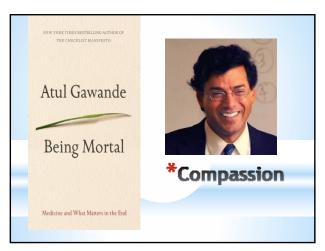


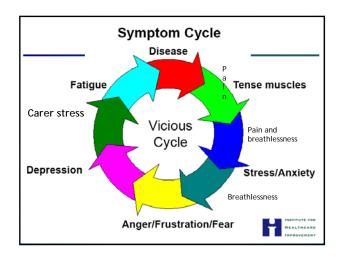


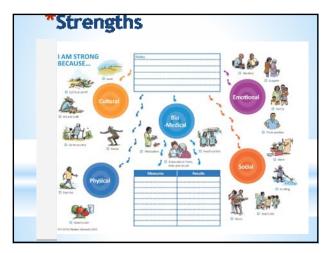


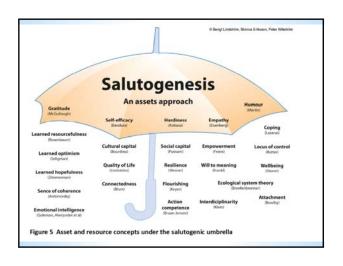


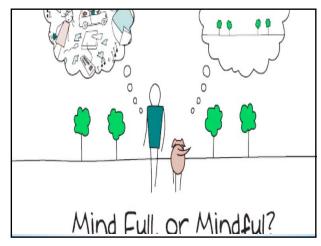












Q: 1. What valued direction does the client want to move in given their current circumstances / challenges?

Q: 2: What is getting in their way?

*Two questions we need to know the answers to

*The sign on your work space needs to say

*How will this (ritual, rule, protocol, policy, procedure, intervention etc) help the "patient" and their whanau?

*Are we doing the right things and are we doing them right?









*We can grow our capabilities and confidence

We know we can heal or harm

Working with People Living with Long-Term Conditions-2015





*Thank you for listeningand thank you for "being there" for the populations you serve!