

Hutia te rito o te harakeke  
Kei whea to Kōmako e Kō  
Kī mai kia ahau  
He aha te mea nui o te Ao?  
Maku e kī atu  
He tāngata,  
He Tāngata,  
He Tāngata!



**Every single  
interaction we have**

**Heals or Harms!!!!**

# The Magic's

- “They listened ..... and created space for us to “be” .. Helped us feel safe to “be”
- They created relationships with us where we felt we mattered !
- They cared for us as people. They were interested in us..... And we were interested in them.
- They celebrated Ormie’s life and he wasn’t just someone with cancer. They became part of “Team Ormie” and were on our side ...
- They were there for us in a scary world we did not understand ...
- They healed our bad experiences with those “menaces”, and gave me confidence to ask for what we needed



**To lose compassion we  
lose what it is to be  
human**



**We Need Person Centred  
Collaborative Care that Fit's  
People's lives**

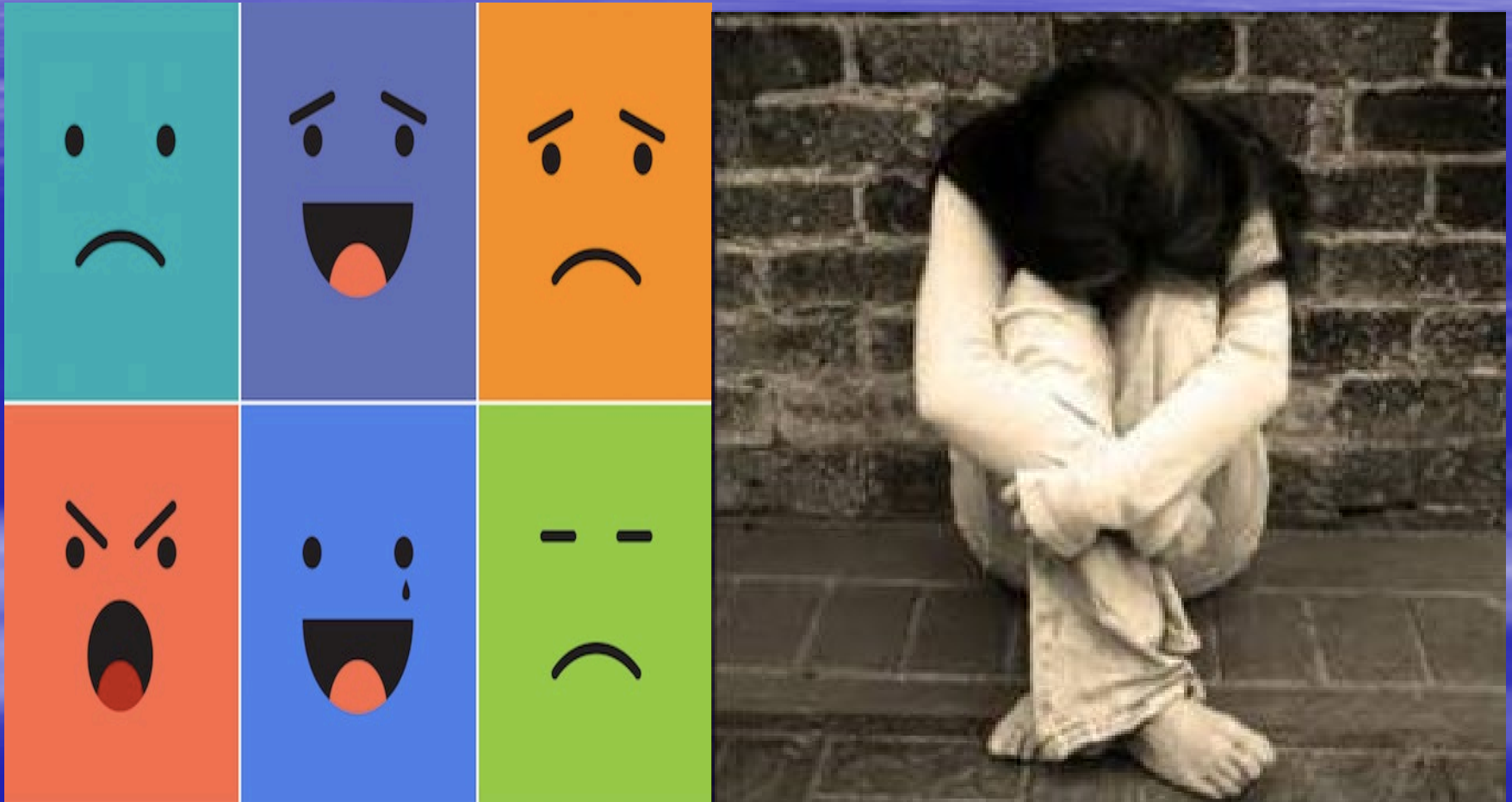
**Minimally Disruptive  
Medicine**



SO.....What do some of our people living with long term conditions say ?



# Emotional cost



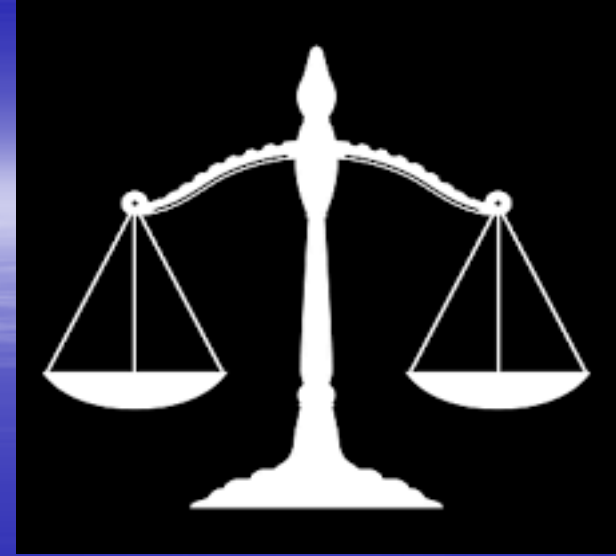
# Cultural cost



**Want it to be like this.....BUT IT FEELS MORE LIKE THIS !**



# Opportunity Costs



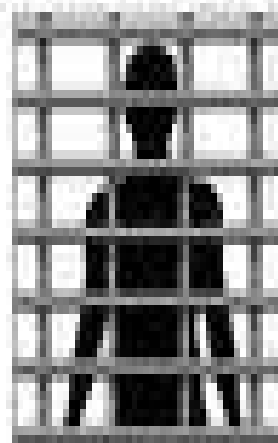
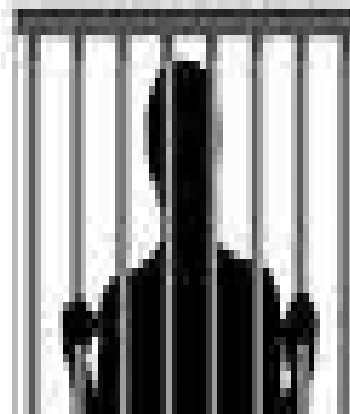
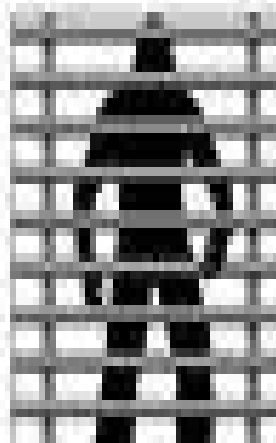
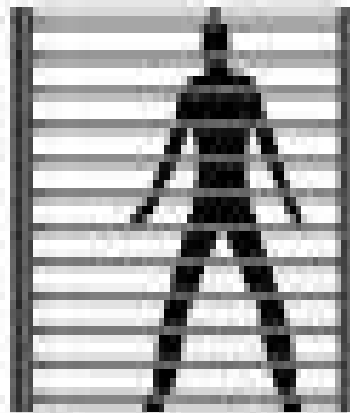
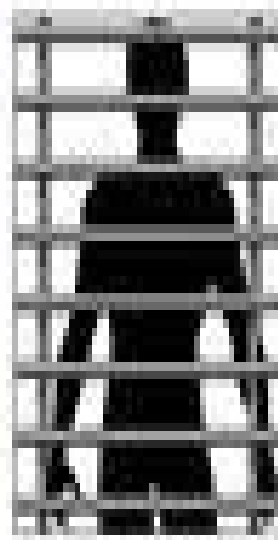
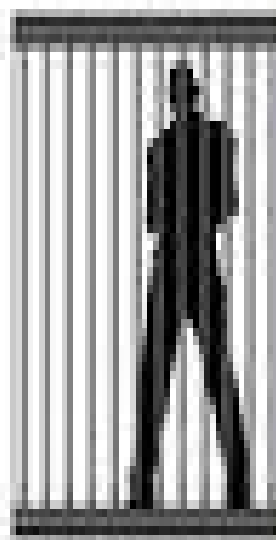
- Pills, treatments/interventions
- Get to clinic appointments
- Time for monitoring, treatments and interventions, appointments
- Focused on my illnesses and trying to manage
- Food for family
- Rent
- Time for paid work or time with whanau
- Living the role I want to fulfil in life

It can be a ten hour day!!!!

And then there is the cost of parking!!!

# PRISON

No choice  
No Autonomy



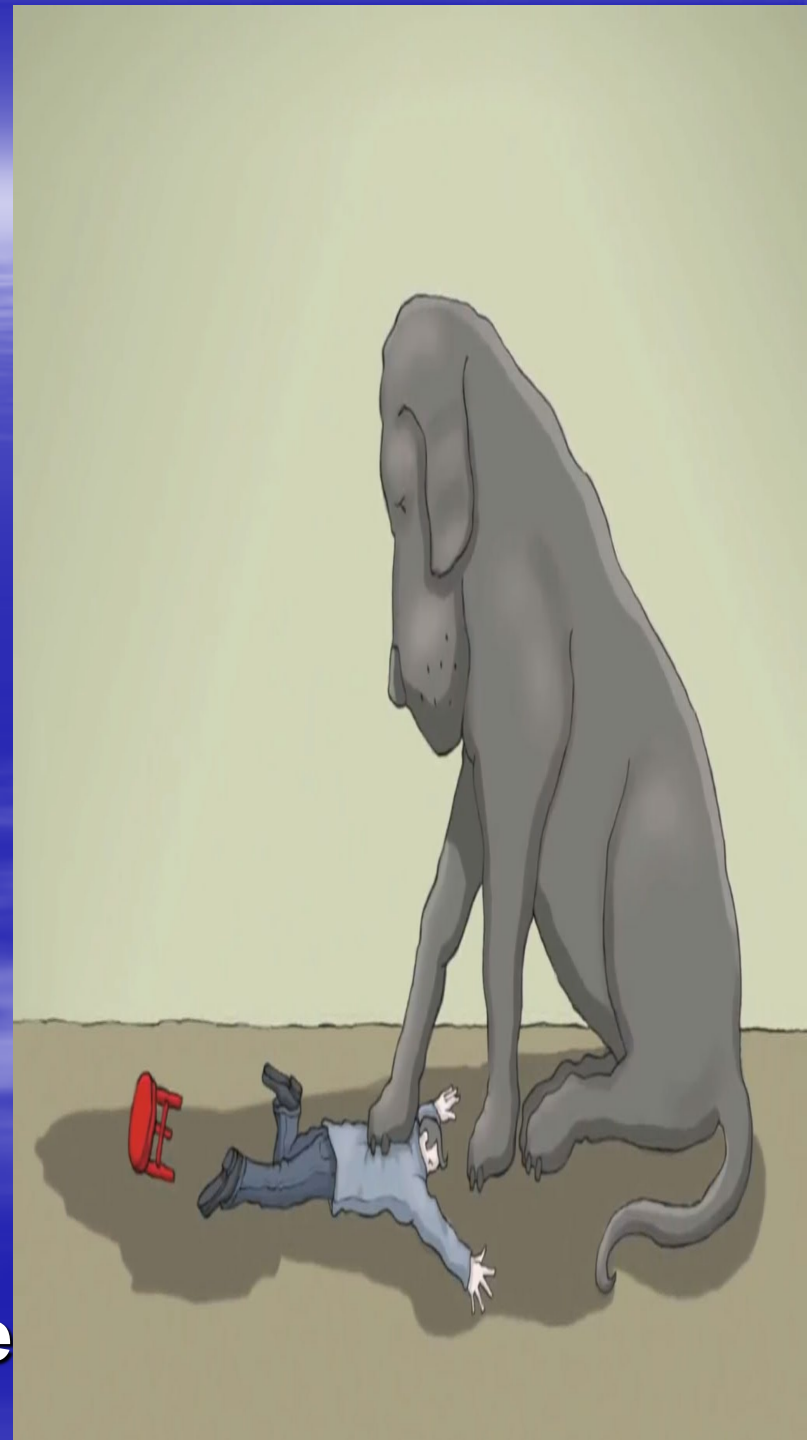
# THE GRIEF WITH DIAGNOSIS & LIVING WITH LTC'S IS REAL AND HUGE

- Loss of fluids
- Loss of foods / salt
- Loss of energy
- Loss of function
- Loss of sex life
- Loss of hair
- Loss of body image
- Loss of heart function
- Loss of control





- **Loss of role in life**
- **Loss of partner**
- **Loss of holidays**
- **Loss of farm**
- **Loss of small home**
- **Threat of rest home**
- **Loss of independence**
- **Loss of drivers license**
- **Loss of connections especially grandchildren**
- **Loss of security**
- **Loss of hope**
- **Constant threat of loss of life**



# Depression is not normal and it won't go away !!!!!

Try to stay strong, your black dog will go away soon.



How would you describe your  
experience ?



# Institutional racism

There's no racism in  
New Zealand

Yeah Right.

ActionStation  
people power change



## Towards health equity: Institutional racism as a policy issue



Gaile Dool, Heather Came and Tim McGeehan  
PHA Special Interest Group: Institutional Racism  
7 October 2014 - Population Health Congress

## CONTACT DETAILS:

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Chair of PHA SIG Institutional Racism  
Auckland University of Technology  
[heather.came@aut.ac.nz](mailto:heather.came@aut.ac.nz)

09 921 999 ext 7799  
021 539 063



# Poor Coordination



**We are just a  
number !**

# Too many providers



- **So Confusing**
- **Can't deal with them all**



# Lack of transport



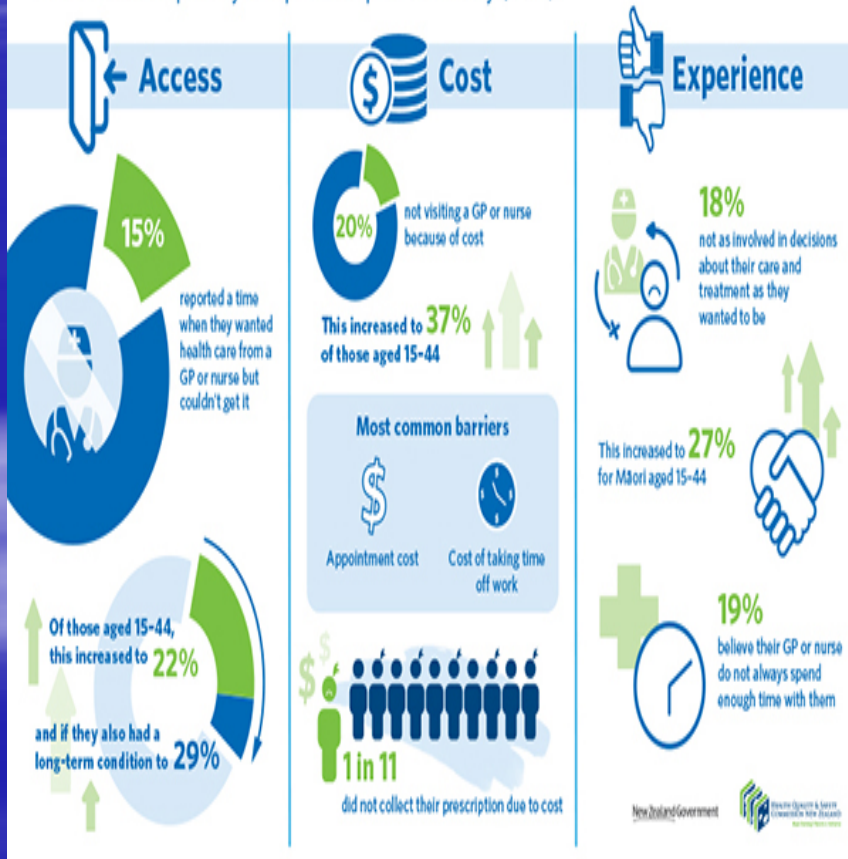
- No car reg
- No bus service
- Appointment  
four hours  
away at 0900?

# Affordability

Atlas of Healthcare Variation

## Health service use: key findings

Results from the primary care patient experience survey (2018).



- Debt
- Cost
- Shame

# Delays in service provision



# LIFE COMPETES WITH HEALTH CARE

**WORKLOAD**

**CAPACITY**

POVERTY &  
DETERMINANTS

COLONISATION


RACISM

TREATMENT  
BURDEN

WHAT CAN  
STRENGTHEN THIS ?







**Doctor, I want  
to choose how  
I'm treated**

**Hmm. You're  
not just ill –  
you're deluded**

New water pill makes him dizzy

Diabetes

Hypertension

Depression

Told off for not taking pills even tho he is

High Cholesterol

Told to check BG but he does and records

Overweight

Doc focuses only on HBA1c

Lower back pain

Pain?  
Insomnia?  
Despair?

Pain in feet

Told < salt, <fat,  
<carbs, get active ,  
exercise, check feet  
... Cant see feet !!!

Worries ... job , deadlines, brings work  
home ... keeps him awake

Loss of job threat to debt , mortgage and  
insurance , bills

Had to ask neighbor  
for lift

Daughter addicted to painkillers

Daughter and two daughters home and  
abused ...

Deemed **“non compliant”**  
Fired from practice

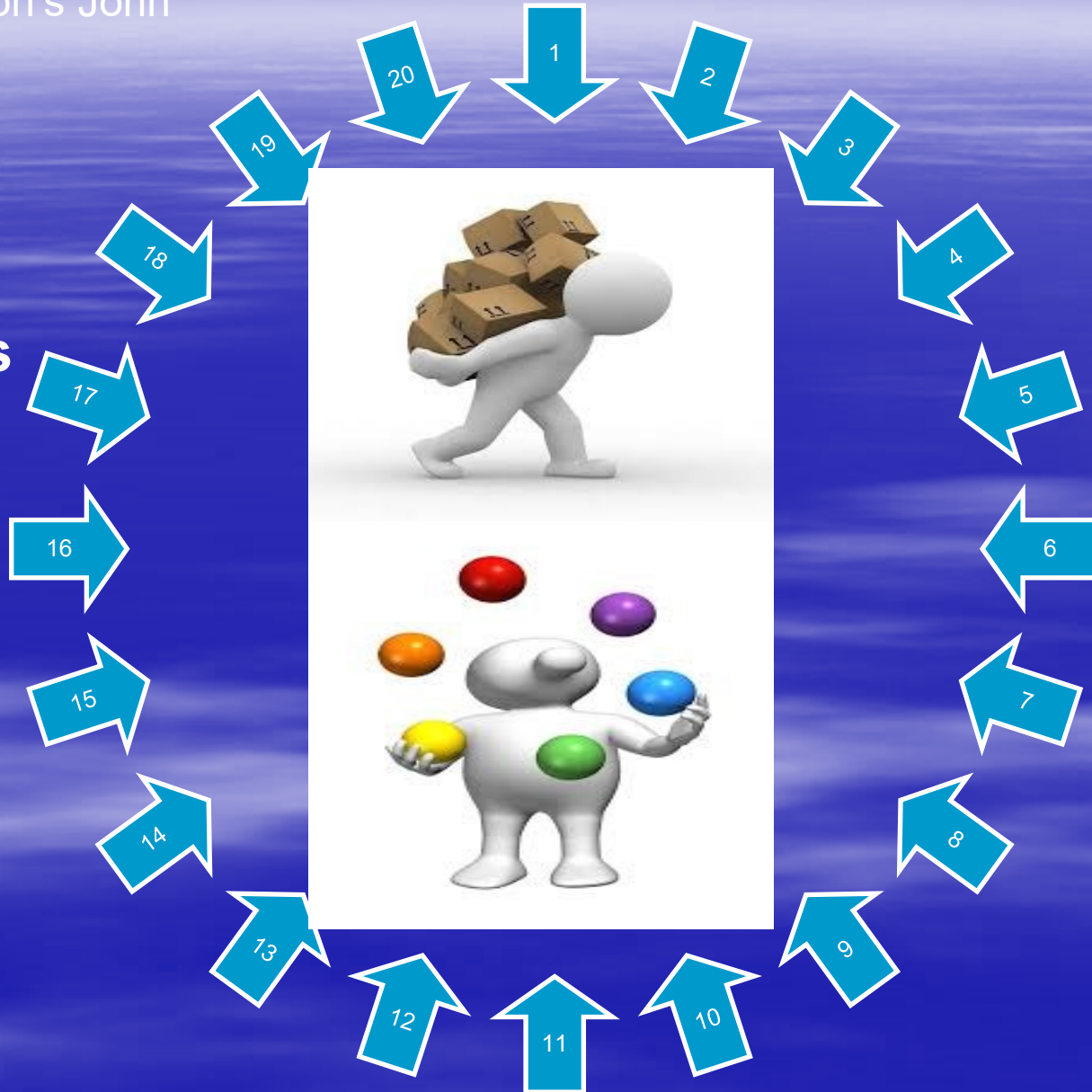
Time off work

Referred to diabetes team

# Meet Hōne..... Hōne is a sign !

Victor Montori's John

**Hōne had  
over 20  
challenges**



# Healthcare has become toxic to Hōne





# We say Hōne is “**non compliant**”

- Hōne has “stopped singing” , we have stopped listening but in health care that is deemed Hōne’s fault
- We, and our health systems, have “**structured non concordance**”



# Our Language is Labelling, Shaming & Blaming

- Non compliant
- DNA's
- Frequent flyers
- Failed Discharge
- Ready to go delay
- Social admission
- Diabetics
- Chronic .....and we always locate the problem in the client



# Non-compliance ... our error ?



- Turn up volume
- Tell them what they must do
- Label them
- Withdraw emotionally
- Stop offering services
- They feel abandoned

# Learned helplessness

## Learned fatalism

Seligman , 1960/ 70's

SELIGMAN'S LEARNED HELPLESSNESS THEORY





# We need a navigator



- Only give information once
- Focus on our journey
- Want control
- Want alternatives
- Want people who “see us “

# Health care is industrialised



**Targets & limited  
resources**

**Structured for acute  
care & single disease**

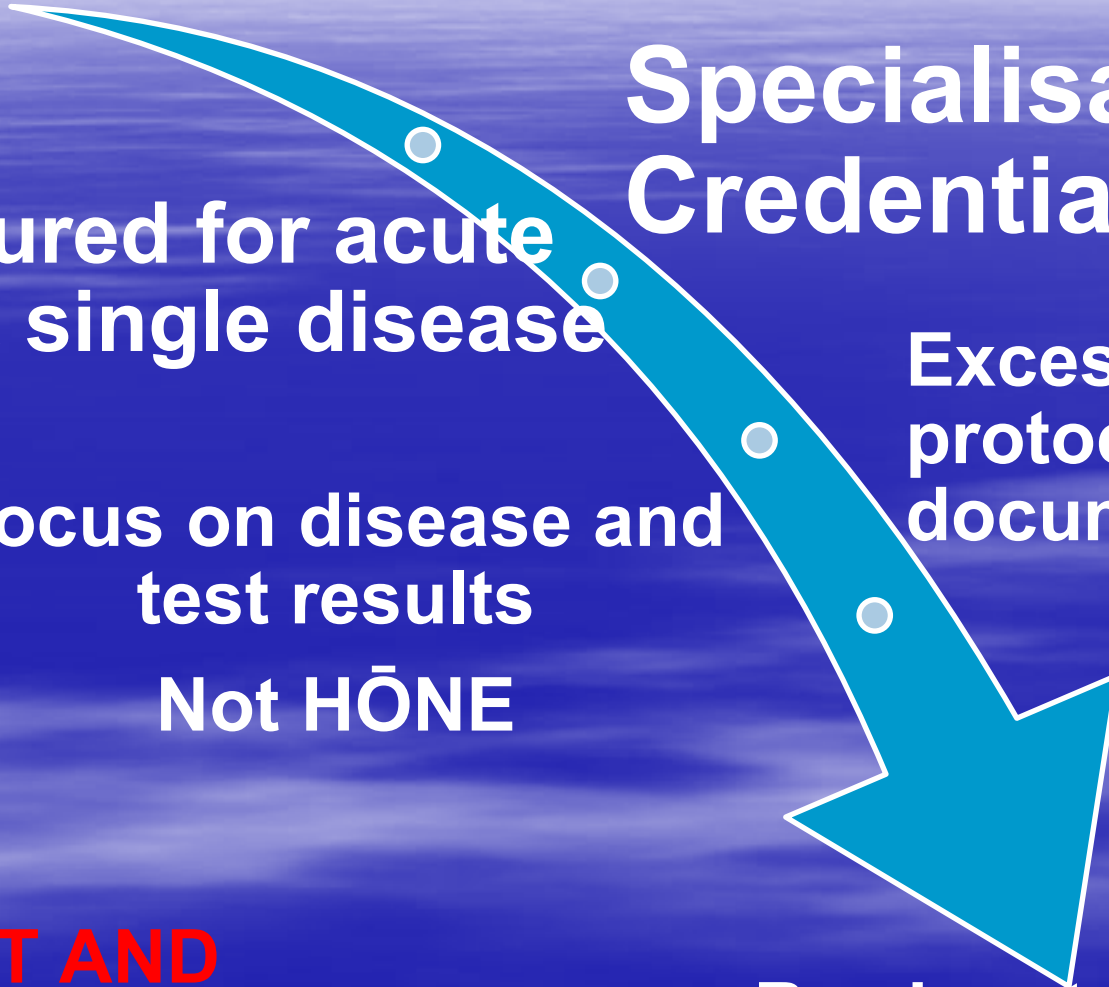
**Focus on disease and  
test results  
Not HÖNE**

**Specialisation &  
Credentialling**

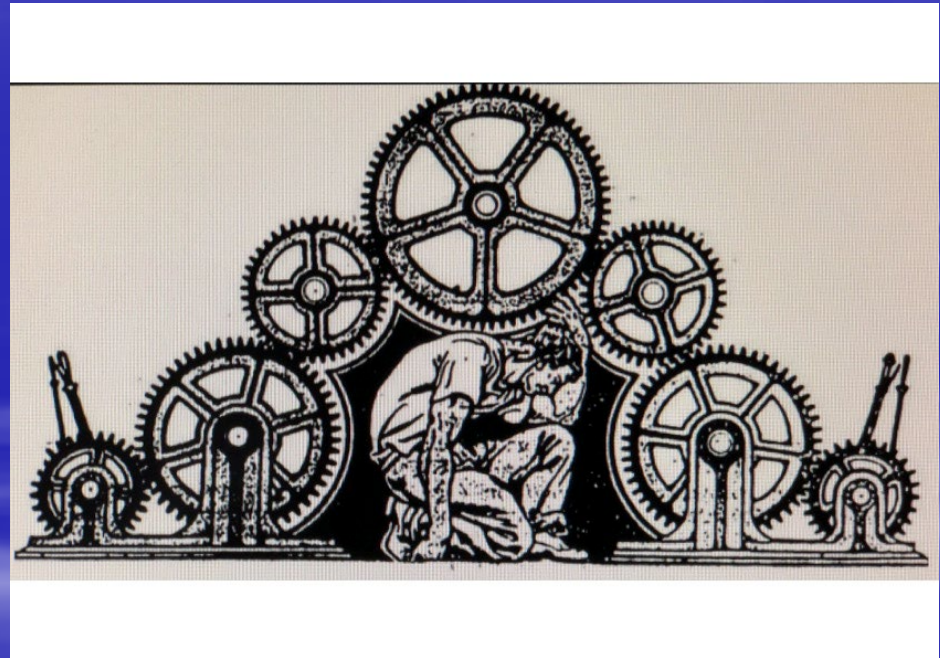
**Excessive  
protocol and  
documentation**

**Barriers to access,  
quality, and internal  
dissonance for us**

**BURNOUT AND  
COMPASSION  
FATIGUE ?**



# Cruel to patients and cruel to us





# What is .....

## But what should it be?

**FROM** doing some  
of the things right  
for some of the  
people some of  
the time ,  
**RESULTING IN**  
**INEQUITY**



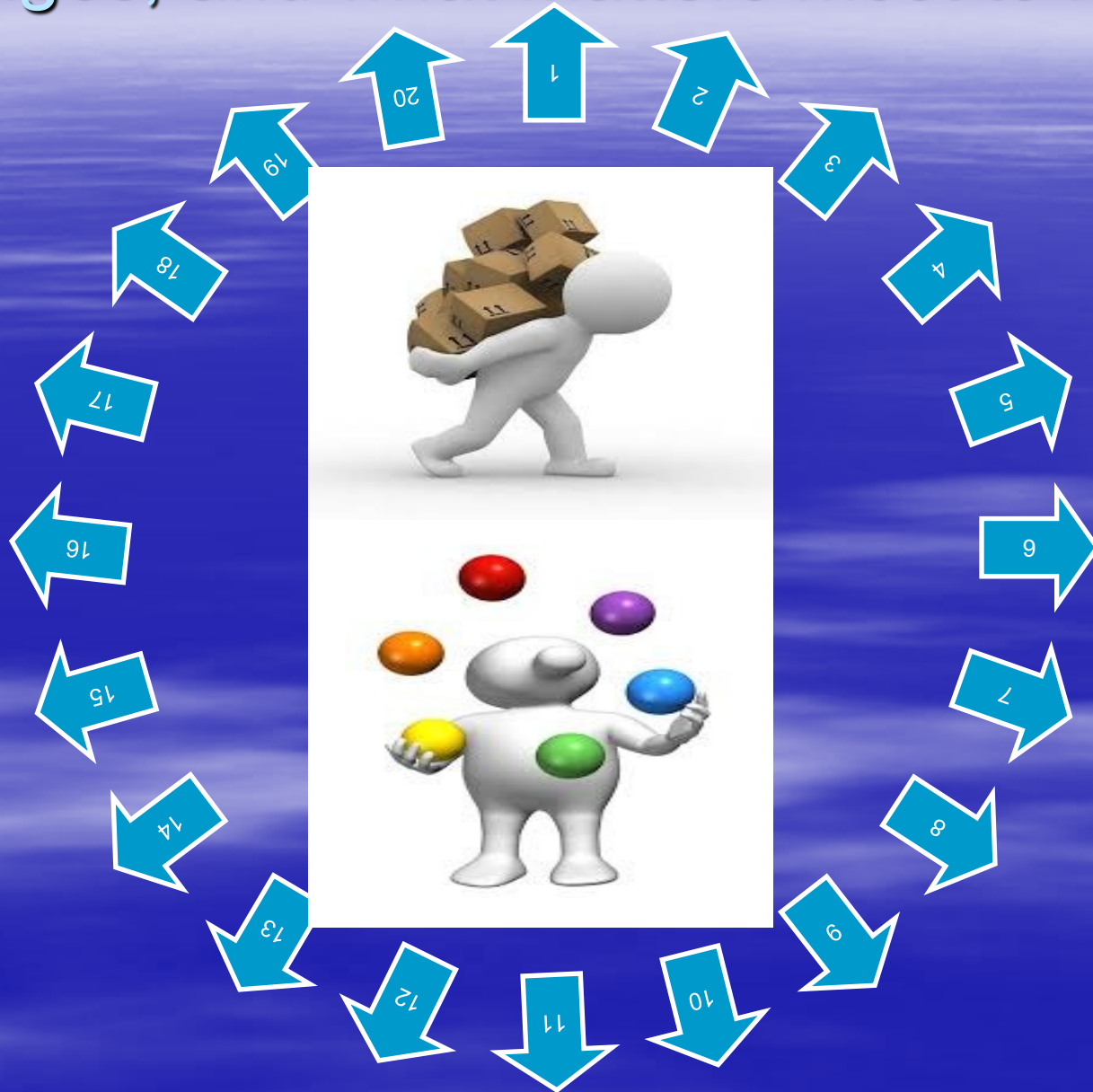
**TO** targeting **AND**  
**WORKING WITH**  
those most in  
need and reducing  
inequity of  
outcome



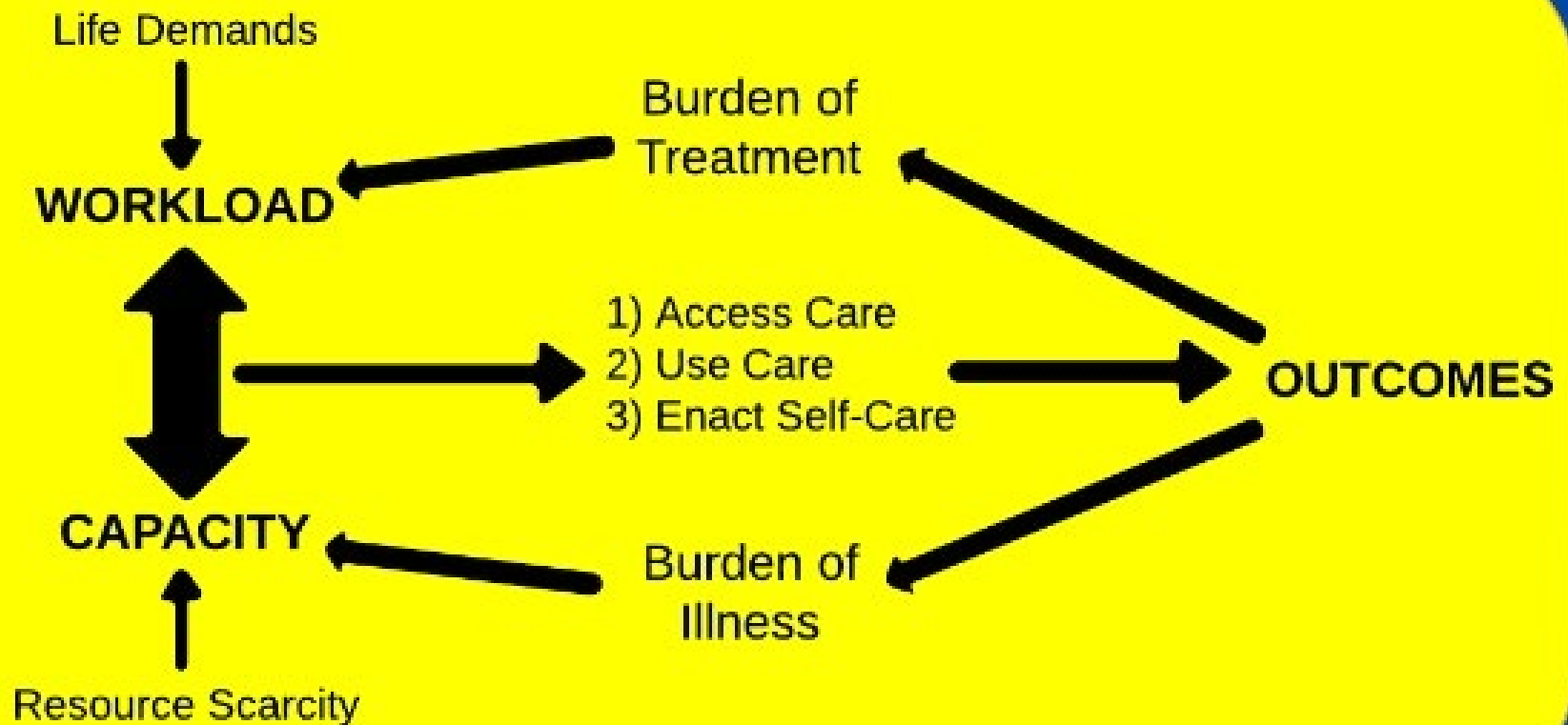
**TO** doing all of the  
things right for all  
of the people all of  
the time  
**ENSURING KIND**  
**COMPASSIONATE**  
**ELEGANT CARE**



We need care that is centred by Honē , his challenges, and what matters most to him



# The Cumulative Complexity Model



Shippee, *J Clin Epidemiol.*, 2012

---

What are you doing to manage your stress?



---

Where do you find the most joy in your life?

---

What else is on your mind today?

## My Life My Healthcare

How does your healthcare fit with your life?



[http://www.mayo.edu/research/labs/knowledge-evaluation-research-unit/programs Minimally Disruptive Medicine](http://www.mayo.edu/research/labs/knowledge-evaluation-research-unit/programs/Minimally%20Disruptive%20Medicine)

MAYO CLINIC | 200 First Street SW | Rochester, MN 55905 | [mayoclinic.org](http://mayoclinic.org)



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MC5733-58

This discussion aid will help you and your clinician talk about how your healthcare fits with your life.





Are these areas of your life a source of **satisfaction**, **burden**, or **both**?

Leave blank if not part of your life	 Satisfaction	 Burden
My family and friends	<input type="checkbox"/>	<input type="checkbox"/>
My work or finances	<input type="checkbox"/>	<input type="checkbox"/>
Free time, relaxation, fun	<input type="checkbox"/>	<input type="checkbox"/>
Spirituality or life purpose	<input type="checkbox"/>	<input type="checkbox"/>
Where I live	<input type="checkbox"/>	<input type="checkbox"/>
Getting out and transportation	<input type="checkbox"/>	<input type="checkbox"/>
Being active	<input type="checkbox"/>	<input type="checkbox"/>
Social media, TV or screen watching	<input type="checkbox"/>	<input type="checkbox"/>
My emotional life	<input type="checkbox"/>	<input type="checkbox"/>
My memory or attention	<input type="checkbox"/>	<input type="checkbox"/>
The food I eat	<input type="checkbox"/>	<input type="checkbox"/>

What are the things that your doctors or clinic have asked you to do to care for your health?

Do you feel that they are a **help**, a **burden**, or **both**?

Leave blank if not part of your life	 Help	 Burden
Take medications	<input type="checkbox"/>	<input type="checkbox"/>
Monitor symptoms	<input type="checkbox"/>	<input type="checkbox"/>
Manage my diet and exercise	<input type="checkbox"/>	<input type="checkbox"/>
Get enough sleep	<input type="checkbox"/>	<input type="checkbox"/>
Come in for appointments or labs	<input type="checkbox"/>	<input type="checkbox"/>
Reduce alcohol use, smoking, etc.	<input type="checkbox"/>	<input type="checkbox"/>
Insurance or support services	<input type="checkbox"/>	<input type="checkbox"/>
Manage stress	<input type="checkbox"/>	<input type="checkbox"/>
Write in any others	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>



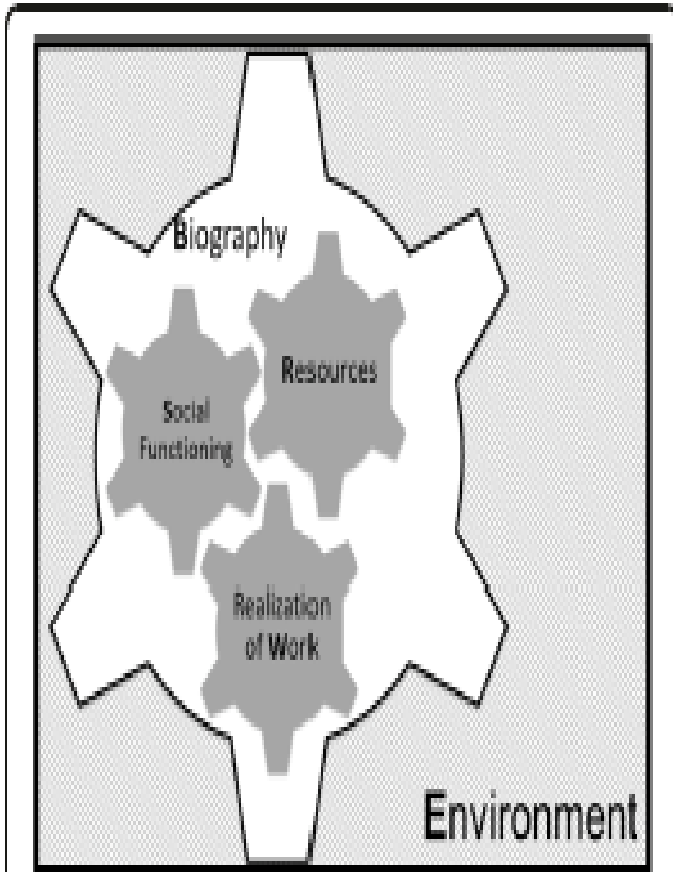


Fig. 2 Theory of patient capacity

- **B.** Biography
- **R.** Resources
- **E.** Environment
- **W.** Work
- **S.** Social functioning

Patient Capacity is complex  
Boehmer et al, 2016

# Good help checklist

If you are involved in the design or delivery of public services or social programmes, you might want to use this simple checklist to get a sense of whether the help you are offering is 'good help'.

Are you:

1. Recognising and building upon the influence and control that each person brings (**power sharing**)?
2. Having conversations that enable people to feel safe and ready to take action for themselves (**enabling language**)?
3. Helping people define their own purpose and plans, and responding to their individual needs (**tailoring**)?
4. Offering practical and emotional support that helps people take and sustain action, then stepping back as they build confidence to take action alone (**scaffolding**)?
5. Helping people connect with and take action with other people they identify with (**role models and peer support**)?
6. Expanding opportunities for people to take action (**opportunity making**)?
7. Sharing information between practitioners and the people being supported (**transparency**)?

# Time for Action

A patient revolution for  
careful and kind care

## Why We **Revolt**

**Victor Montori**




# Patient revolution

<https://patientrevolution.org>



We are a citizen movement to champion...

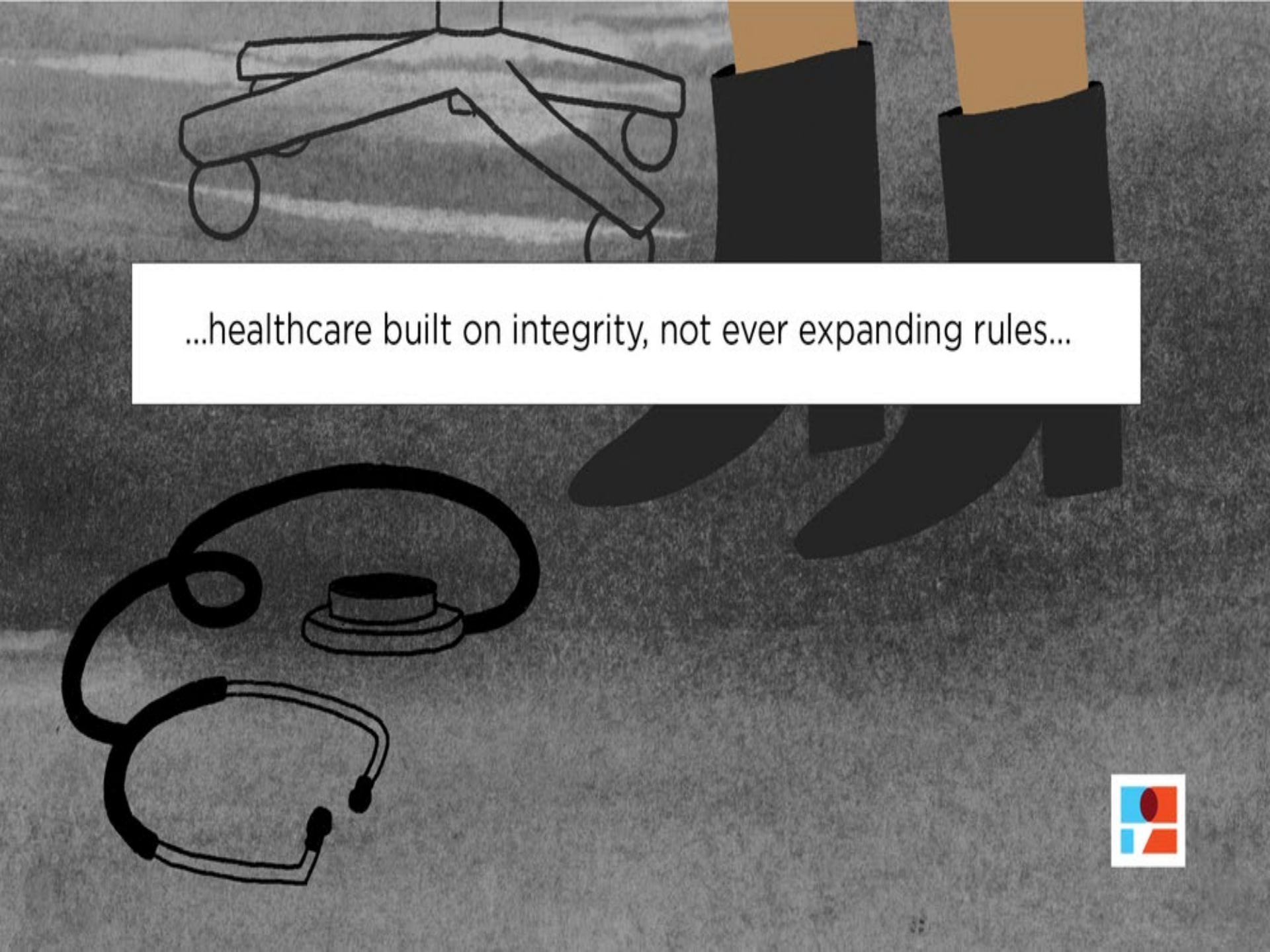


An illustration of a person with reddish-brown skin and a white head covering, wearing a white hospital gown with blue patterns. They are holding a black power cord that is plugged into a wall outlet. An orange cord is also plugged into the outlet. The background is a textured grey wall. The person is sitting on a bed with a purple blanket. The overall style is minimalist and graphic.

...healthcare where stories about your life are welcome...





The background of the slide is a dark grey, textured surface. In the upper right, there is a stylized illustration of a person's lower legs and feet, wearing black boots. In the lower left, there is a black line drawing of a stethoscope. A white rectangular box is positioned in the center of the slide, containing the text.


...healthcare built on integrity, not ever expanding rules...



...healthcare that recognizes the work of being a patient...






An illustration of a person's legs and feet from the waist down. The person is wearing a white skirt with blue dashed patterns and orange leggings. Their feet are also orange and are standing on a grey surface marked with white horizontal lines. A speech bubble originates from the left, containing the text "...healthcare for you, not people *like* you...".

...healthcare for you, not people *like* you...



An illustration showing a female doctor with dark skin and hair in a braid, wearing a white lab coat over a purple shirt. She is gently touching the shoulder of an elderly male patient with yellow skin, who is wearing a black vest over a grey shirt. The patient has a sad expression. They are in a simple room with a grey wall and a white door frame. A white banner with text is positioned in the center.

...healthcare built on love and solidarity, not greed.



# Measure and Monitor your Unconscious Biases

- Take the blinkers off
- Be Brave
- Ask the hard questions

Project Implicit

<https://implicit.harvard.edu/implicit/takeatest.html>





# “Notice and call racism”

- Be courageous
- Name it when you see it
- Call your colleagues, patients and whanau and the system to account



**We have to be “hope  
generating” not “spirit breaking”**



# Join the patient revolution

- We have to share decision-making and support people to have control and choice of how they live their lives ... especially the last 1000 days



# Go to work every day with the

- perspective of a patient
- spirit of an artist...
- heart of a healer
- courage of a lion



The Doctor, 1891. Luke Fildes



# Thank you, for listening, and “being there” for your people!

- Thank you to all the patients and staff for sharing their precious time and experience with me
- Thank you Victor Montori for instigating a patient revolution

Tēnā koutou,  
Tēnā koutou,  
Tēnā koutou katoa



He aha te mea  
nui o te ao ?  
He Tāngata  
He Tāngata  
He Tāngata