



# Living with Risk: Finding the Balance

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# “AI Updates”

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- MCH Friendship Place grant



- Book with Jennifer Carson, PhD  
(and thanks for added content)



- *Accidental August* (Anne Hills)



# Disclosures

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The speaker has no affiliations that would constitute a conflict of interest for this presentation.

# Outline

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- Share 8 basic principles around the concept of risk
- Describe both straightforward and more challenging (COVID-19) examples of risk negotiation
- Explore the complex and multifactorial nature of risk in long-term care
- Imagine a path forward, along with needed operational, infrastructural and macroscopic enablers
- Briefly address a question raised after Dallas and Sarah's 3/3 talk

A few  
definitions...

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**Risk** - the chance that something will happen that is *different* from what we expect

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**Downside Risk** - the chance that something will happen that is *worse* than what we expect

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**Upside Risk**- the chance that something will happen that is *better* than what we expect

# Principles #1 & 2

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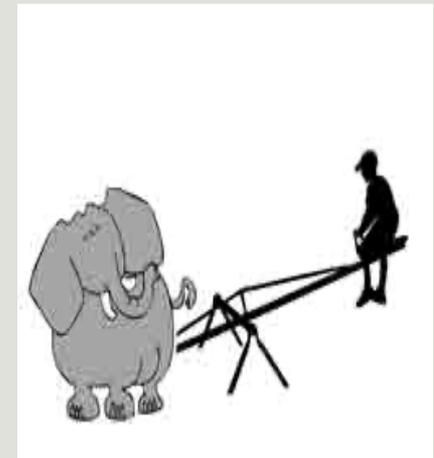
- Every action we take will involve some degree of both upside and downside risk; the proportion of each will vary with the situation.
  
- Every action we ***do not*** take will *also* involve some degree of upside and downside risk.

# Two more definitions

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**All-or-none thinking** - seeing every situation as requiring only one of two opposing solutions, without any nuance, flexibility or middle ground

**Surplus safety** - excessive concern with downside risk, relative to upside risk (i.e., most of long-term care policy!)



# Principle #3

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Surplus safety is commonly associated with a loss of critical thinking skills.

(Karen Stobbe's story)





A straightforward example of upside and downside risk:

*Mercy Parklands  
Auckland, New  
Zealand*

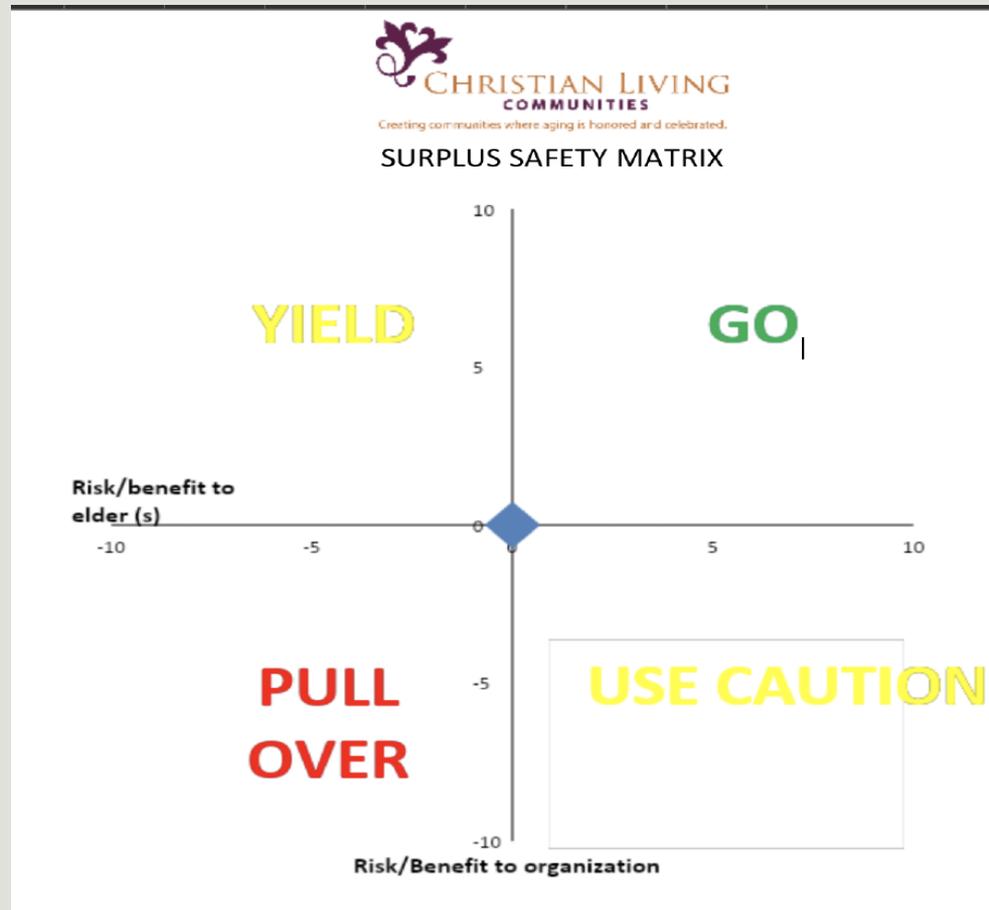
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# Example:

## Surplus safety assessment tool

### Christian Living Communities





And now, a *much*  
more complex  
example of risk:

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# SARS-CoV-2: The Downside

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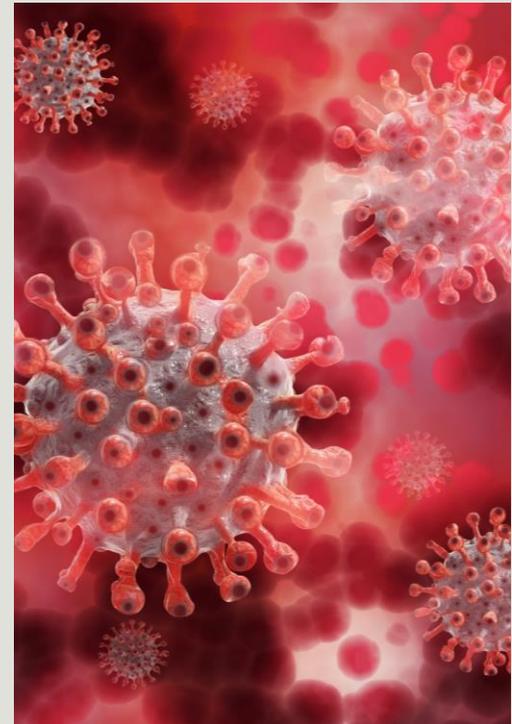
Highly infectious

High morbidity and mortality in older people and those with chronic medical conditions

Nearly 175,000 deaths in US nursing homes (as of 3-4-21)  
(<https://covidtracking.com/nursing-homes-long-term-care-facilities>)

Nursing homes house only 1% of population, but represent 34% of deaths

Isolation/lockdown seemed like a necessary response, but...



# Isolation/Lockdown: The Downside

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Loneliness/social isolation (physical, psychological and cognitive effects)

Loss of family contact

Loss of touch

Weight loss and subnutrition

Poor sleep

“Failure to thrive”

Increased distress and use of physical and chemical restraints

“40,000 excess non-COVID deaths” (Stephen Kaye, PhD, UCSF)

## In-Room Quarantine: Additional Downside Risks

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**Decreased mobility** → decreased appetite, poorer sleep, deconditioning/loss of muscle strength, worsening balance

**Distress** → inappropriate use of psychoactive medications → sedation, decreased appetite, increased gait imbalance and fall risk, risk of atelectasis and hyperthermia, etc. etc.

# Principle #4

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“The only risk-free human environment  
is a coffin.”

-Bill Thomas, MD

# Principle #5

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We can never eliminate risk, we can only *negotiate* it, balancing the upside and downside as best as possible for each individual situation.



Example: Global Aging presentation on visitation by Stephen Cornelissen, CEO, Mercy Health Australia



# Principle #6

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The balance of upside and downside risk can change over time and needs to be re-examined periodically, to be sure the best approach remains in place.



## And...Principle #7

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We should never ask, "What is the risk of doing (something)?" without also asking "What is the risk of *not* doing it??"



# But...Principle #8!!!

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Risk is actually *much more than* a two-sided coin; it has multiple facets!!



## Two questions for you:

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Were the excess COVID-19 infections and deaths in nursing homes simply due to poor infection control practices?

and/or

Were the excess deaths simply due to improperly balancing isolation versus social engagement?



# Other contributing factors

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## **Operational**

Rotating staff, agency staff

Inadequate pay and sick leave, need to work more than one job

Lack of adequate PPE, testing, contact tracing

## **Physical**

Multi-bedrooms, shared toilets and showers

Large and/or crowded living areas

Little ability to distance in common areas

Little/no access to outdoors



# Other contributing factors

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## Macroscopic

Prevalence of infection in the surrounding community

Behavior of local citizens

Long-term care reimbursement

Distribution of reimbursement dollars within different homes/corporations

Inflexible regulations

Inconsistent leadership/messaging from government at all levels

Etc., etc., etc.

# Green House COVID study

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COVID infections and deaths in Green House homes were only a tiny fraction of those seen across traditional US nursing homes.

(Zimmerman, et al., *JAMDA*, 2021)

Do you think this was *only* due to superior infection control policies and procedures??

Zimmerman,  
Westley, &  
Patton (2006)



**GETTING TO MAYBE:** THIS BOOK IS FOR THOSE WHO ARE NOT HAPPY WITH THE WAY THINGS ARE AND WOULD LIKE TO MAKE A DIFFERENCE. THIS BOOK IS FOR ORDINARY PEOPLE WHO WANT TO MAKE CONNECTIONS THAT WILL CREATE EXTRAORDINARY OUTCOMES. THIS IS A BOOK ABOUT MAKING THE IMPOSSIBLE HAPPEN  
**HOW THE WORLD IS CHANGED.**

- “Disasters occur when complex issues are managed or measured as if they are merely complicated or even simple” (p. 10).
- In complex systems, **relationships** and **dialogue** are key.
- We need to learn to live and work with uncertainty; to channel our “inner sailor” vs. “inner cowboy/cowgirl.”

SIMPLE	COMPLICATED	COMPLEX
<b>Baking a Cake</b>	<b>Sending a Rocket to the Moon</b>	<b>Supporting a Person Living with Dementia (or LTC pandemics)</b>
The recipe is essential	Rigid protocols or formulas are needed	Rigid protocols have a limited application or are counter-productive
Recipes are tested to assure easy application	Sending one rocket increases the likelihood that the next will also be a success	What serves to support one person's well-being does not guarantee success with another person
No particular expertise is required, but experience increases success rate	High levels of expertise and training in a variety of fields are necessary for success	Expertise helps but only when balanced with presence and responsiveness to each person
A good recipe produces nearly the same cake every time	Key elements of each rocket MUST be identical to succeed	Every person is unique and must be understood as an individual
The best recipe gives good results every time	There is a high degree of certainty of outcome	Uncertainty of outcome remains
A good recipe notes the quantity and nature of the 'parts' needed and specifies the order in which to combine them, but there is room for experimentation	Success depends on a blueprint that directs both the development of separate parts and specifies the exact relationship in which to assemble them	Can't separate the parts from the whole; essence exists in the relationship between different people, different experiences, different moments in time

# For affected residents who cannot remember to maintain precautions

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- Engage in room as much as possible with meaningful things that could interest the person.
- Create an optimal feeling of comfort in one's surroundings.

(Aguiar and Power, 2021)



- Optimize room identification and wayfinding in the living area, especially if moved there from another locale.

## For affected residents who cannot remember to maintain precautions - 2

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- Look at attempts to walk or exit as expressing needs and work to understand how they can be best fulfilled.
- Reframe “behaviors” as legitimate responses to a trying situation. Dementia did *not* cause the situation, but it affects one’s ability to cope with it.
- Discuss illnesses and quarantines from past eras (measles, polio, etc.).
- Discover what people may need when they want to leave the room, and if needs can be fulfilled in the room, arrange for it.

## For affected residents who cannot remember to maintain precautions - 3

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- Encourage any non-affected residents in the area to keep their doors closed to prevent the person from entering (some use “Dutch doors”).
- **Help people to walk** (1:1 may be required during the contagious phase), to engage, direct and assist with hygiene as much as possible.
- Two infected residents in close contact are not a primary concern.
- Other staffing patterns for one or more people walking (from March Madness): Zone or “Box-and-1”.

## For affected residents who cannot remember to maintain precautions - 4

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- Remember that peak viral shedding is from ~2-3 days before illness onset until ~5 days of illness have passed with most contagion resolving at ~9 days (there are outliers, but this is the main time frame.) During this time, many affected people will be feeling poorly and will not be up and about.
- Use frequent reminders, handwashing and “stay in room” signs. (Precautions might be more palatable is presented as “for your protection.” --Karen Stobbe, 3/20)
- Encourage masks for those who will wear them.

## For affected residents who cannot remember to maintain precautions - 5

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- Physical restraints are dangerous and will increase distress and the risk of injury and death. This was proven decades ago and should not be a consideration here.
- Walking is a *normal, daily human activity* What is abnormal is having people in a place where they cannot walk freely!
- Advice from my SentryCare call 3-15:
  - Heather Landry, CNA: “Walk with people!”
  - Chris Cheek, CEO: “Staff empowerment is the best infection control.” (Engage your team’s creativity!!)

For affected residents who cannot remember to maintain precautions - 6

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Sedating drugs are also potentially dangerous to use.

There is *NO* drug that helps people remember to only walk in certain areas, maintain a 6-foot distance from others or wash their hands.

Their only effect in this situation is *sedation* (which is a dangerous practice in a person who may already be seriously infected) and would be expected to greatly increase their risk of dehydration, injury and death.

# Lessons Learned

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1. Negotiating risk is **complex**.
2. It involves dialogue with multiple stakeholders (especially elders and direct support workers).
3. It requires *flexibility and individualization* to best succeed.
4. Many of the important precepts of the culture change movement help create the increased flexibility and individualization needed for this.

# Lessons Learned

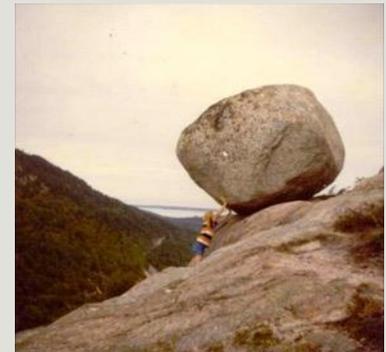
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5. People are unique, as are their desires and their tolerances for downside risk.
6. Blanket, one-size-fits-all regulations, policies and procedures will always result in a degree of harm or infringement to some, if not most people involved.
7. We should work from principles and values, rather than hard-and-fast rules.
8. Not every factor is within our control, but many are (use Anne Basting's "Yes, and..." approach).

# And lastly...

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While the pandemic is the biggest challenge we have faced in long-term care, many other discussions of negotiating upside and downside risk (e.g. dietary preferences, alarm removal, going outdoors, etc.) become *much* easier to achieve using the above approaches.



# Thank you. Questions?

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