

# Walking Around With Cancer: The Psychological Burden of Active Surveillance

**ANCan/Us Too AS Support Group  
November 3, 2021 @ 8pm EST**

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# Prostate Cancer

## It is estimated that in Canada in 2020:



Canadian  
Cancer  
Society

- 23,300 men will be diagnosed with prostate cancer.
- 4,200 men will die from prostate cancer.
- 1 in 9 men will be diagnosed with prostate cancer during his lifetime.

## It is estimated that in the US in 2020



American  
Cancer  
Society

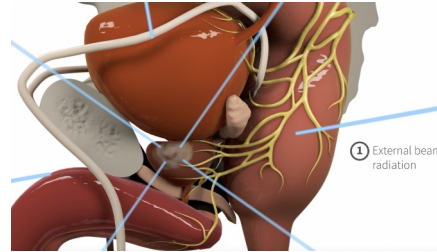
- 248,530 will be diagnosed with prostate cancer
- 34,130 will die from prostate cancer
- 1 in 8 men will be diagnosed with prostate cancer during his lifetime.



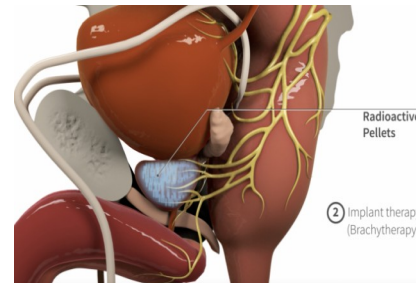
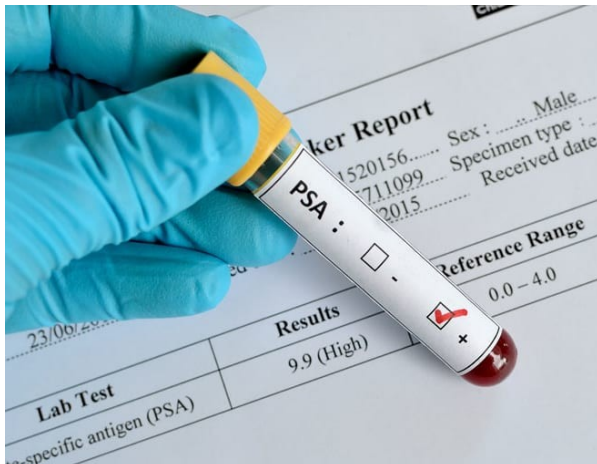
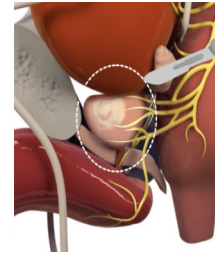
The 5-year survival rate for most people with local or regional prostate cancer is **nearly 100%**.

# Prostate Cancer Survival

- Prostate cancer mortality in the USA has fallen by about 40% since 1993
- The two most probable reasons for this reduction:
  - 1) Early detection (PSA)
  - 2) Improved treatments.



- Radical Prostatectomy
- Robotic RP
- IMRT/VMAT
- Brachytherapy
- Focal Therapy
- ADT
- Combination Therapy



# However...

- Due to the sensitivity of PSA testing, many newly diagnosed men had biologically indolent disease and are unlikely to die from PC
- Modeling studies have also suggested that the risk of PSA-detected prostate cancer being “overdiagnosed” is about 67%, ***leading to overtreatment***
- Treatment results in side-effects that negatively impact HRQOL

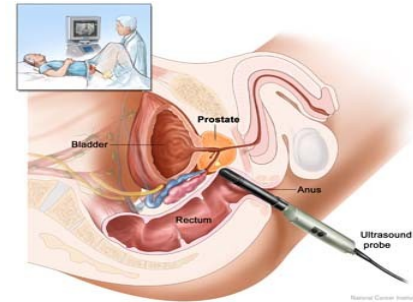
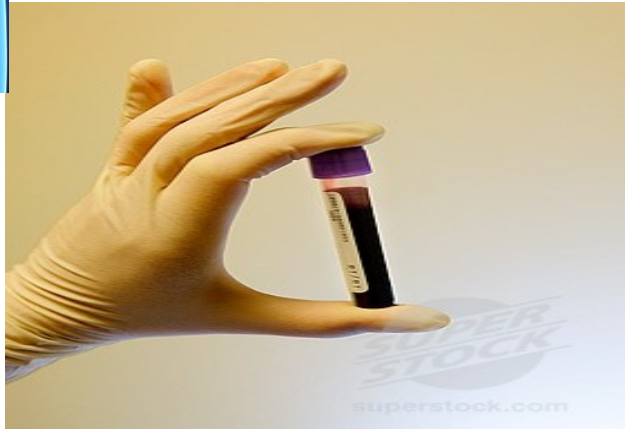
OVERALL, early detection is likely producing both mortality and benefit and overdiagnosis

- We were clearly overtreating prostate cancer

# Possible Solution: Active Surveillance

- Eligible Patients:

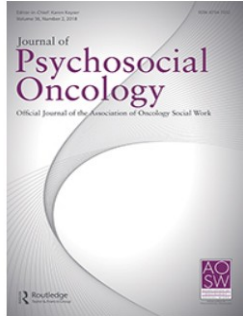
- No more than 3 cores
- No more than 50% per core
- Gleason 6 (or & (3+4=7, <10% of 4)
- PSA <10ng/ml
- Have localized PC (T1 or T2)
- Negative DRE



# Uptake of AS

- In the US between 2004-06 only 10% of low-risk patients were managed via AS
- In the US between 2010-13, 40% of low-risk cases were managed via AS
- Among men >75, the rate of AS in this population was 76% during this time period.
- There is significant variation in the uptake of AS across American practice sites.
  - registry from Michigan varied significantly across practices from 27% to 80%.
- Globally, multiple studies report reductions in patients with low-risk disease undergoing RP
  - In Sweden from 2009 to 2014 low-risk patients managed via AS increased from 40% to 74%

# Factors influencing AS uptake



Journal of Psychosocial Oncology

ISSN: 0734-7332 (Print) 1540-7586 (Online) Journal homepage: <https://www.tandfonline.com/loi/wjpo20>

**Psychological distress and lifestyle disruption in low-risk prostate cancer patients: Comparison between active surveillance and radical prostatectomy**

Andrew G. Matthew, Orit Raz, Kristen L. Currie, Alyssa S. Louis, Haiyan Jiang, Tal Davidson, Neil E. Fleshner, Antonio Finelli & John Trachtenberg

# Factors Influencing AS Uptake: Urologist

	Frequency	1 (not at all)	2	3	4	5 (very much)	P Value (Trend test)
<b>Urologist*</b>	<b>AS (%)</b>	4.55	2.27	3.41	10.23	<b>79.55</b>	<b>0.0009</b>
	RP (%)	5.94	7.92	14.85	20.79	<b>50.5</b>	
<b>Friends*</b>	AS (%)	<b>62.96</b>	16.67	11.11	5.56	3.7	<b>0.0446</b>
	<b>RP (%)</b>	<b>48.05</b>	19.48	10.39	11.69	10.39	
<b>TV/Radio/Newspaper*</b>	<b>AS (%)</b>	<b>67.92</b>	9.43	13.21	3.77	5.66	<b>0.019</b>
	RP (%)	<b>79.31</b>	15.52	3.45	1.72	0	



# Factors Influencing AS Uptake:

## No difference in anxiety/depression

Instrument Score	AS	RP	P Value (t-test)
<b>STAI</b>			
N	89	103	<b>0.2736</b>
Mean (SD)	32.70(11.41)	30.98(10.24)	
Range	20.00-60.00	20.00-57.00	
<b>CESD</b>			
N	87	107	<b>0.3717</b>
Mean (SD)	7.90(8.46)	6.84(7.92)	
Range	0.00-36.00	0.00-44.00	
<b>PANAS Positive Affect</b>			
N	90	107	<b>0.2499</b>
Mean (SD)	36.04(8.03)	37.34(7.65)	
Range	18.00-50.00	9.00-50.00	
<b>PANAS Negative Affect</b>			
N	90	107	<b>0.5475</b>
Mean (SD)	14.50(5.93)	14.03(5.07)	
Range	0.00-38.00	9.00-36.00	

# Factors Influencing AS Uptake: Specific Anxiety

	Frequency	1 (not at all)	2	3	4	5	6	7	8	9	10 (very much)	P Value (Trend test)
Fear of dying*	AS (%)	21.43	17.86	14.29	1.19	11.9	7.14	7.14	4.76	3.57	10.71	0.0118
	RP (%)	17.43	10.09	6.42	6.42	11.93	3.67	11.01	6.42	5.5	21.1	
Fear of metastasis*	AS (%)	13.41	10.98	10.98	9.76	17.07	7.32	7.32	2.44	6.1	14.63	<.0001
	RP (%)	8.41	3.74	4.67	1.87	8.41	6.54	11.21	18.69	8.41	28.04	
Erectile dysfunction*	AS (%)	17.07	6.1	12.2	6.1	14.63	3.66	9.76	10.98	6.1	13.41	0.0163
	RP (%)	7.69	5.77	7.69	4.81	9.62	9.62	18.27	9.62	3.85	23.08	
Having a tumor in my body*	AS (%)	29.27	10.98	10.98	7.32	14.63	1.22	7.32	8.54	1.22	8.54	0.028
	RP (%)	25.23	6.54	5.61	8.41	8.41	5.61	8.41	11.21	5.61	14.95	

# Active Surveillance Uptake: Conclusions

- Urologist have the greatest influence on patients choosing AS
- Radical Prostatectomy patients reported greater anxiety related to fear dying, metastasis, having a tumor in their body, and ED
- Patients on AS experience fewer physical side-effects (e.g. Urinary incontinence, Sexual Dysfunction)
- However, what is the experience of AS after making the treatment decision?

# Active Surveillance and Anxiety

- No statistically significant impact on survival/mortality
- AS patients experience less impact on quality of life
- The majority of studies report low levels of anxiety and depression
- The majority of AS patients experience decreasing anxiety over time
- Range between 2-18% of AS patients sought treatment without disease progression
- Okay...but what is it like walking around with cancer

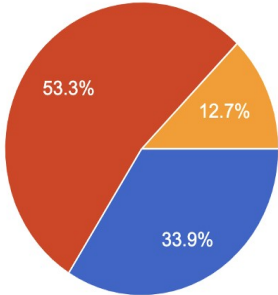
# Active Surveillance and Anxiety Specific Health Worry

	Health worry	AS	RP	P Value
Worry about dying	More than before Tx	<b>26 (30%)</b>	19 (17%)	(0.009**)
	Same as before Tx	54 (61%)	73 (65%)	
	Less than before Tx	8 (9%)	21 (18%)	
Worry about future health	More than before Tx	<b>38 (44%)</b>	31 (27%)	(0.006**)
	Same as before Tx	42 (48%)	62 (55%)	
	Less than before Tx	7 (8%)	20 (18%)	

# Active Surveillance and Anxiety

Are you anxious on AS?

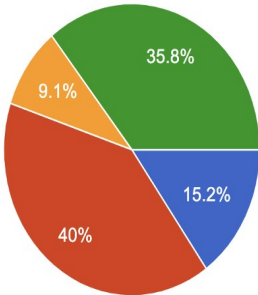
165 responses



- Yes.
- No.
- Uncertain.

If yes, were you anxious before diagnosed with prostate cancer?

165 responses



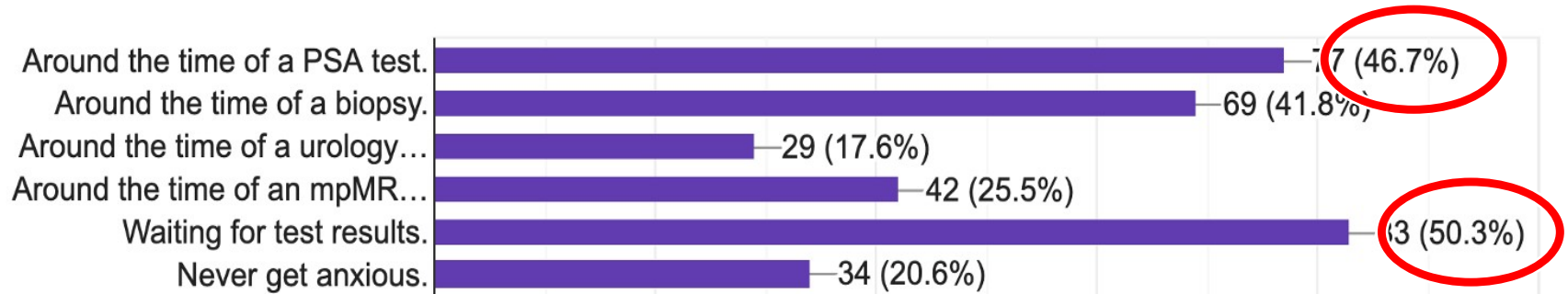
- Yes.
- No.
- Uncertain.
- I am not anxious on AS

*AnCan/Us Too and Active Surveillance Patients International (N=165)*

# When do you experience AS Anxiety?

When do you become anxious? (Check all that apply.)

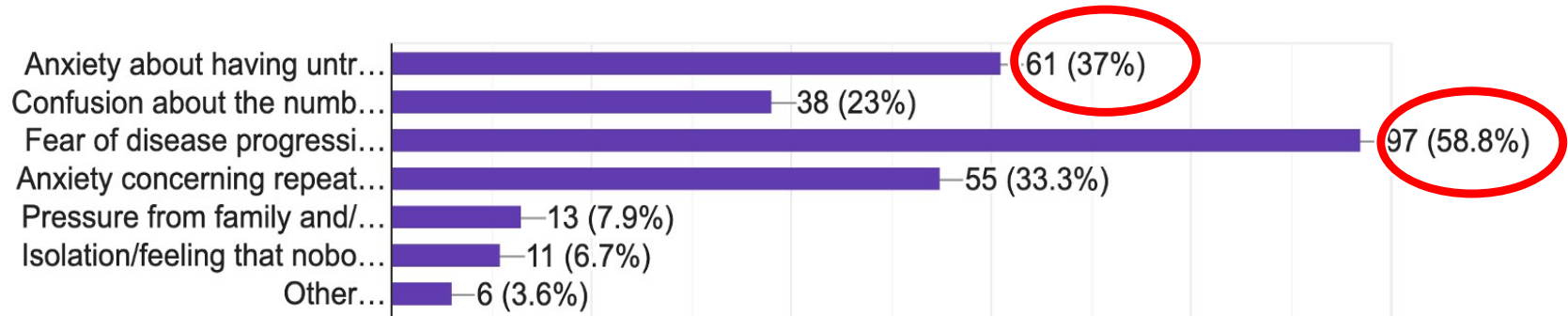
165 responses



# What is the nature of the AS Anxiety?

What have you found most challenging about being on active surveillance? (Check all that apply.)

165 responses





# “Walking around with cancer”

- Anxiety, like all mental health domains, is on a continuum
  - Uncomfortable to Severe
- Few patients can say that being on Active Surveillance does not result in any anxious moments (e.g. Triggers)

So...how can you walk around with cancer and experience anxiety less often and with reduced intensity  
( i.e. reduce the amplitude and frequency of anxiety)

**ANSWER:** Get to know Anxiety and How We Cope

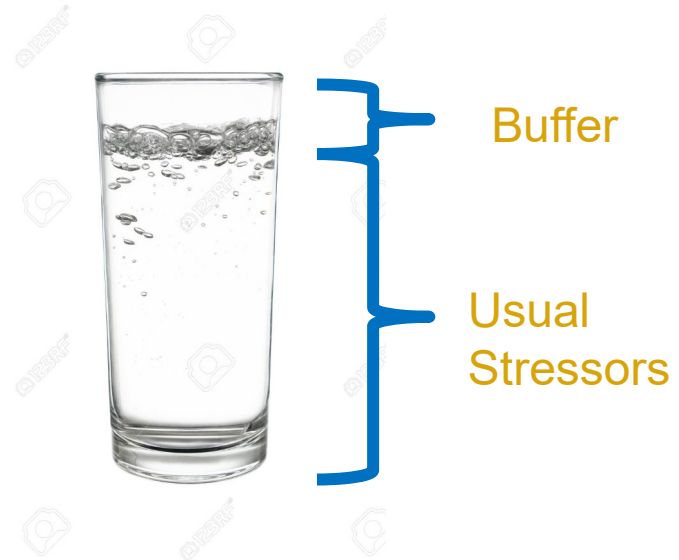
# Limited capacity to cope

- Our ability to cope is not infinite
- Our “Coping Vessel” can only hold so much.



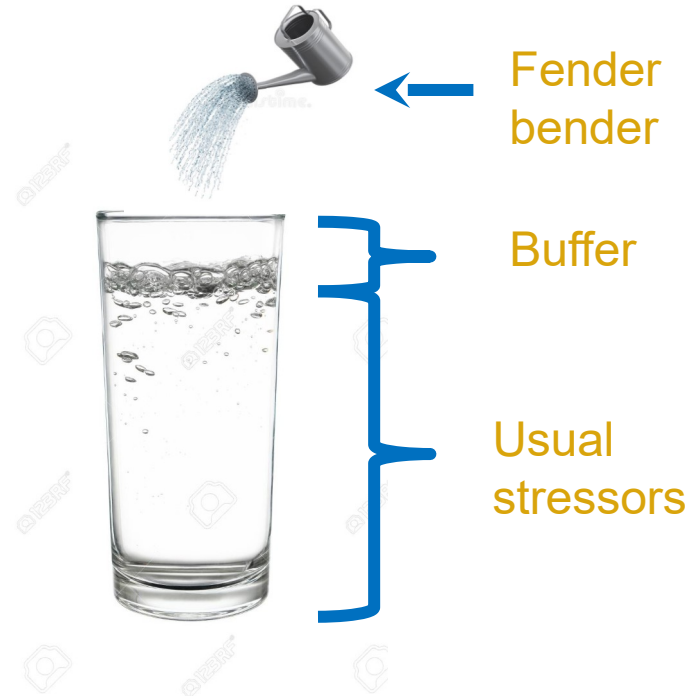
# Limited capacity to cope

- The diagnosis of prostate cancer and being on Active Surveillance does not release us from our usual stressors:
  - **Being an attentive partner**
  - **Parenting or Grandparenting**
  - **Work Demands**
  - **COVID**
  - **Finances and taxes**
  - **Traveling abroad**
  - **Volunteering**
  - **Organizing a social occasion**



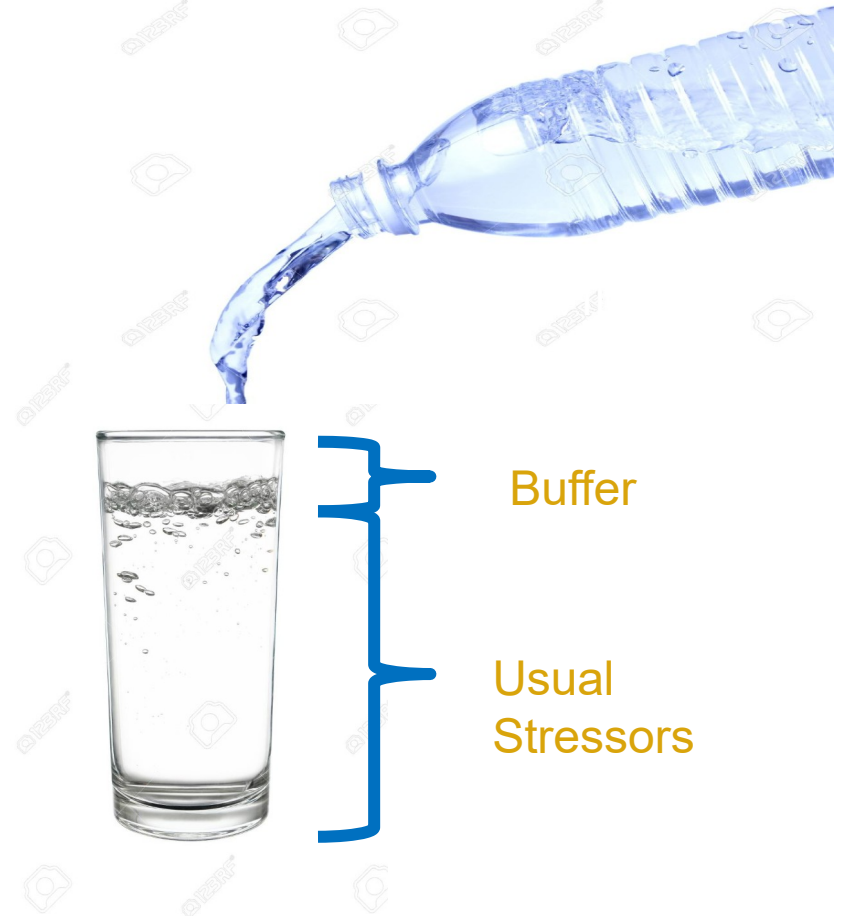
# Successfully Coping

- Our buffer allows for incidental stressors



# Challenged Coping

- Coping with Active Surveillance
  - Requires more space than a fender bender
  - Potentially requires more space than available in our buffer

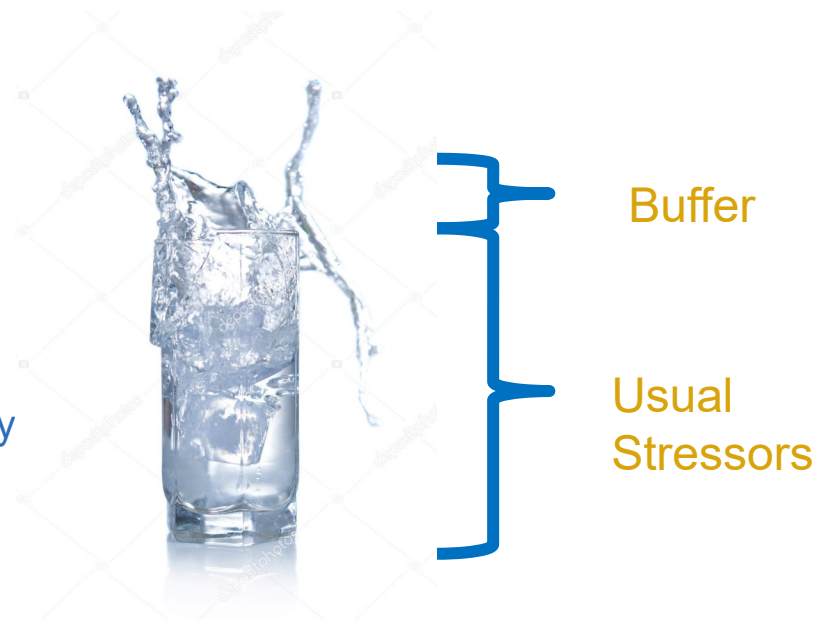


# When Coping Strategies are Overwhelmed

When our "Coping Vessel" overflows we become overwhelmed

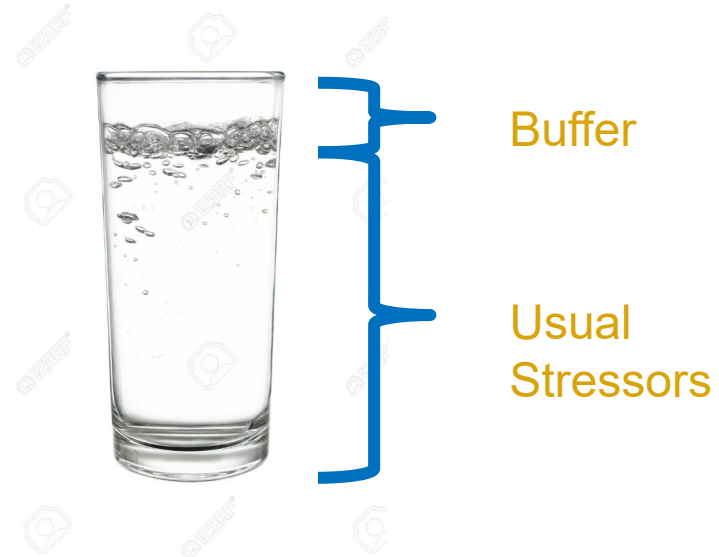
- Feel out of control
- **ANXIETY**

Importance of protecting our coping capacity from becoming overwhelmed




# Approaches to Coping

- 1) Understanding anxiety
- 2) Making space for major stressors
- 3) Identify anxieties and organize according to controllability
- 4) Employ Problem/Emotion/Meaning Focused Coping



# Anxiety and Depression

## ANXIETY

- 
- Difficulty dealing with Lack of Control
  - Difficulty dealing with Uncertainty
  - Helplessness

F  
L  
I  
P

## DEPRESSION

- 
- Despair
  - Hopelessness
  - Worthlessness
  - Guilt
  - Shame



# Step 1: Understanding Anxiety

# Step 1: Understanding Anxiety

Threat

# Step 1: Understanding Anxiety



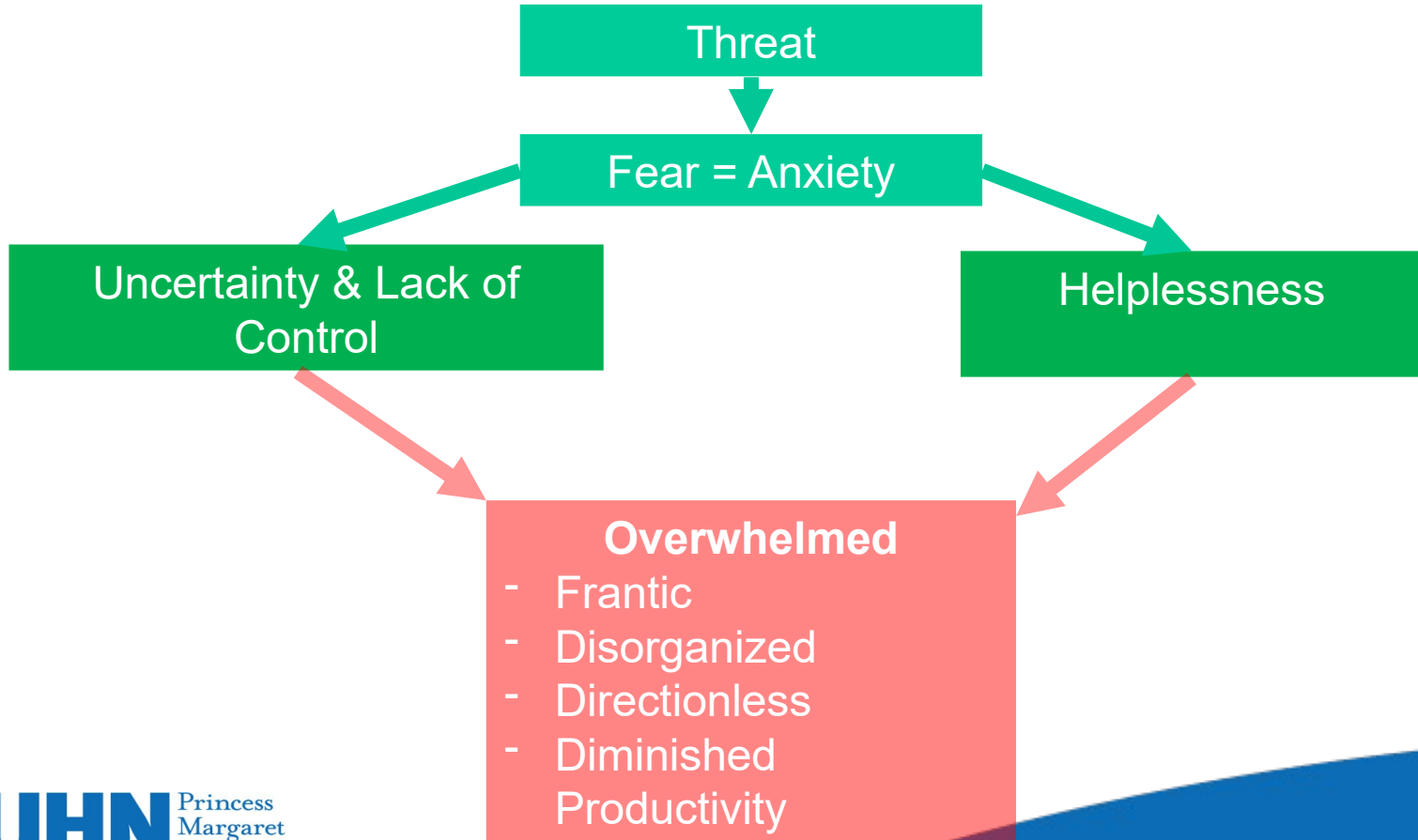
# Step 1: Understanding Anxiety



# Step 1: Understanding Anxiety



# Step 1: Understanding Anxiety



# Step 2: Make Space for Major Stressors

- Identify your usual stressors
- Prioritize stressors
  - Most important
- Organize your stressors
  - what needs to be done now
  - what can be delayed
  - what can be dropped completely



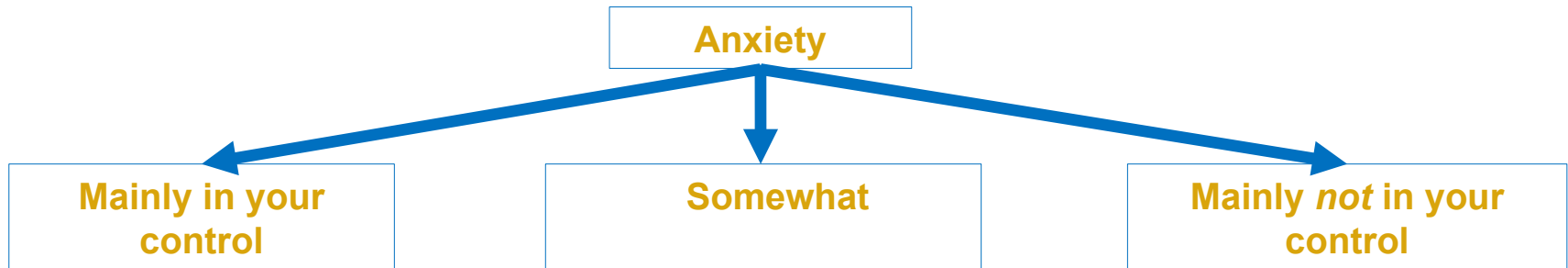
Increase your  
Buffer

Usual  
Stressors

# Step 3: Identify - Controllable vs Not controllable

1) Take some time to identify what concerns are causing you stress or anxiety

2) Divide anxieties in to what is controllable and what is not in your control



3) Knowing what is in your control and what is not in your control will help guide you in choosing ***type of coping approach/strategy***



# Step 4: Use Empirically-Based Approaches to Coping

## 1) Problem-Focused Coping

- Strategies focused on the problem itself

## 2) Emotion-Focused Coping

- Strategies focused on the emotions related to the problem

## 3) Meaning-Focused Coping

- Strategies focused on the meaning of the interaction between you and the problem

**THE MOST EFFECTIVE COPING  
RESPONSE TO A POWERFUL PROBLEM  
(ACTIVE SURVEILLANCE) IS TO COMBINE  
ALL THREE COPING APPROACHES**

# Problem-Focused Coping

- Based in the **rational** and the **logical**
- Critical thinking and Problem-solving

## ***Problem-Focused Coping Check List***

1. Break each problem down into smaller parts
2. Brainstorm options that can help address the problem.
3. Identify the pros and cons of each option.
4. Narrow down to the best option you have.
5. Begin to solve the component parts
6. Cross off tasks as you do them – combat feelings of helplessness.
7. Solve the problem

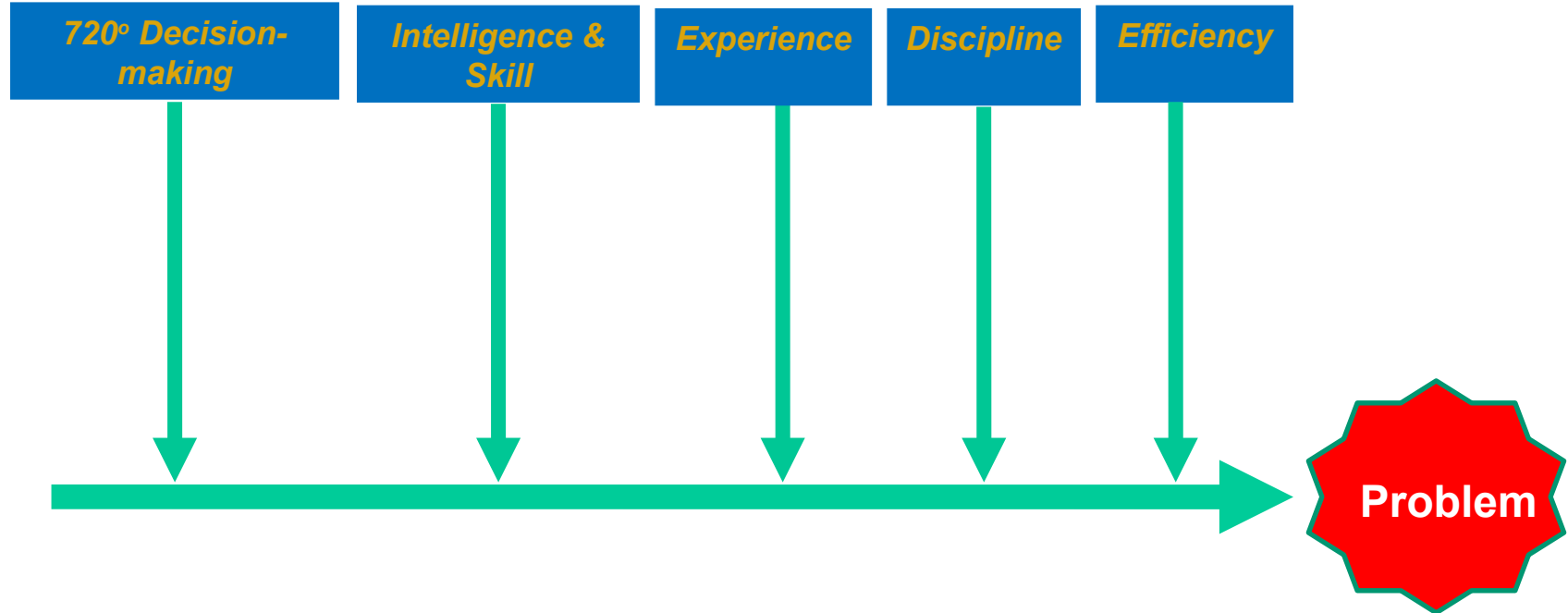
# Problem-Focused Coping

**Stereotypically a Male/Masculine Approach to Coping**

***Problem-focused approach is designed to maintain control and mitigate uncertainty (and avoid anxiety)***

- ***720° decision-making***
- ***Intelligence to hone skill***
- ***Experience***
- ***Discipline***
- ***Efficiency***

# Problem-Focused Coping



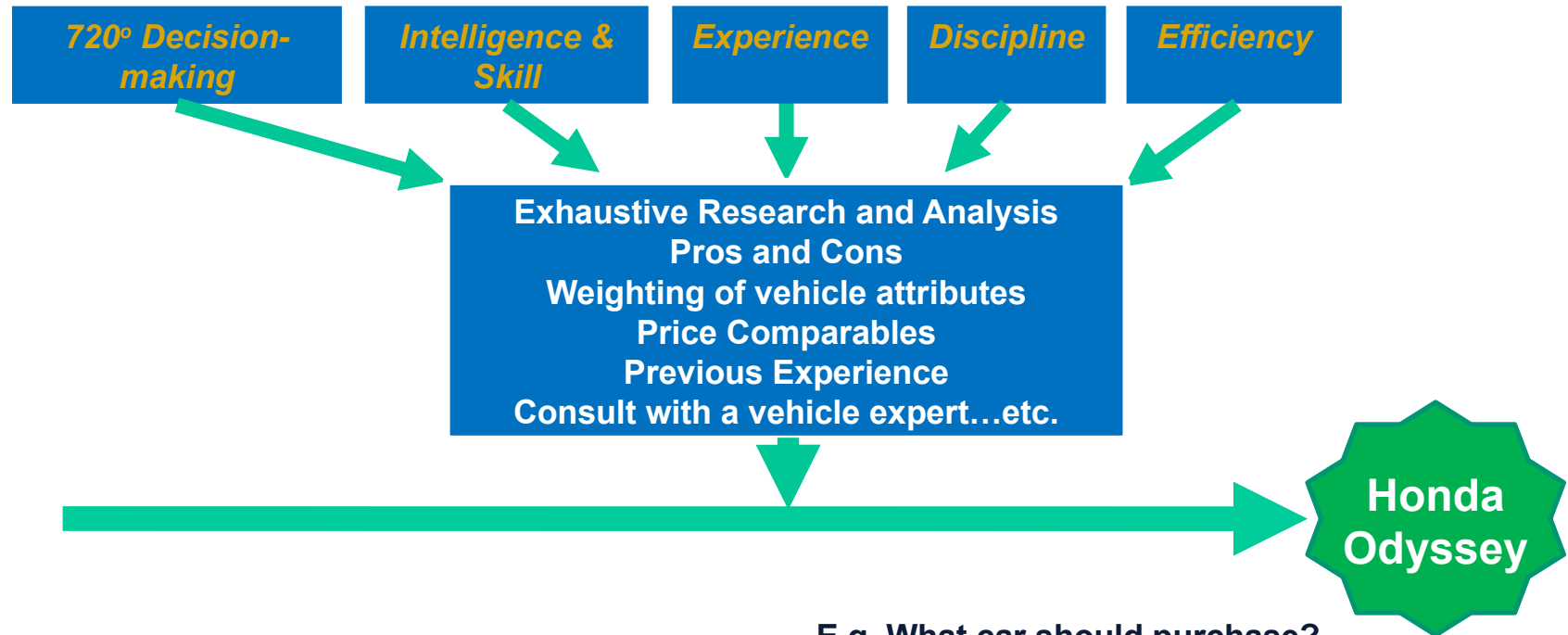
E.g. What car should purchase?

# Problem-Focused Coping



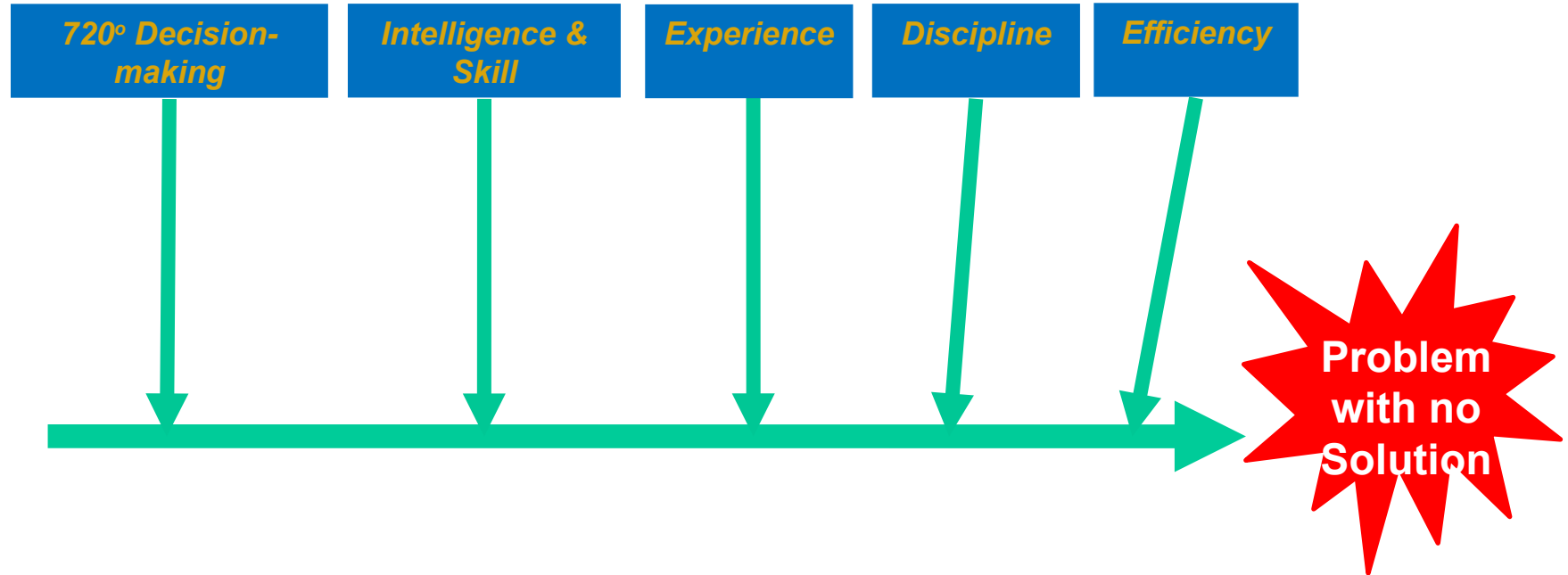
E.g. What car should purchase?

# Problem-Focused Coping



E.g. What car should purchase?

# Problem with No Solution



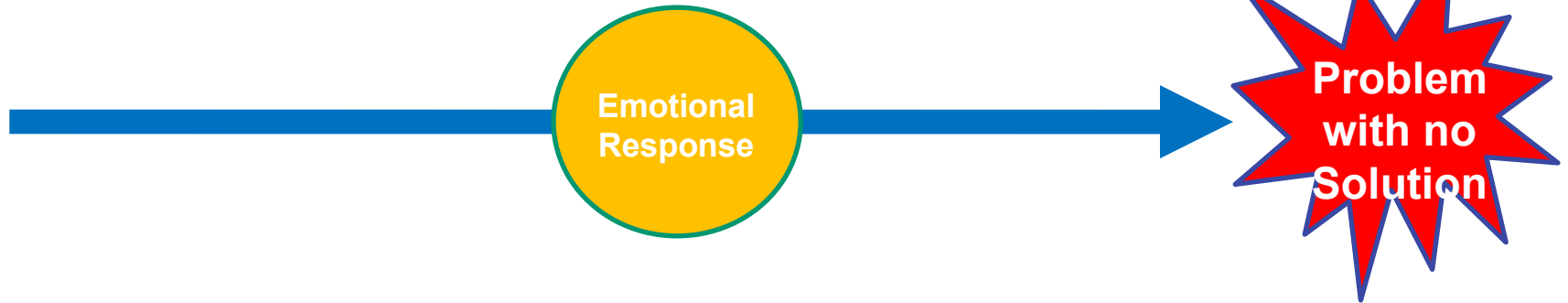
E.g. A diagnosis of cancer

# Problem and Emotion-Focused Coping

Shift focus from solving the problem  
(which is not fully solvable and beyond our control)

TO

Focusing on our *emotional response* to the problem  
(which is in our control)



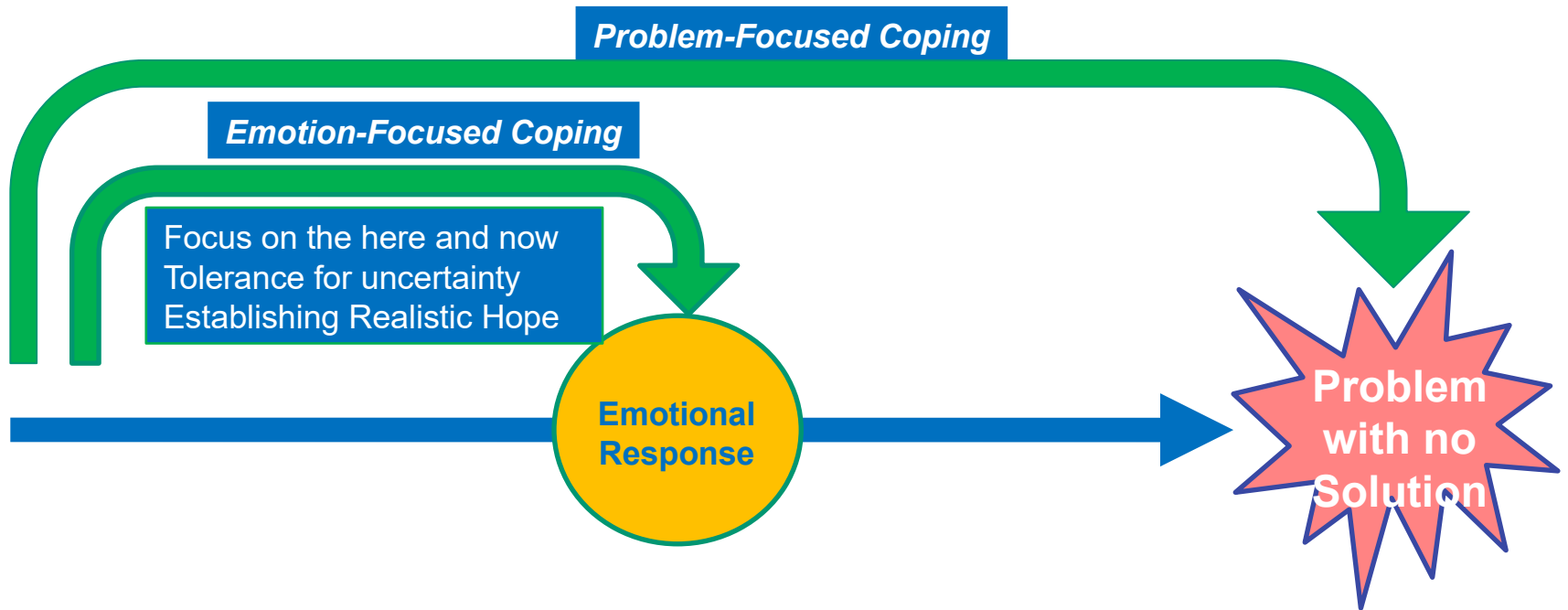
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# Problem-Focused Coping

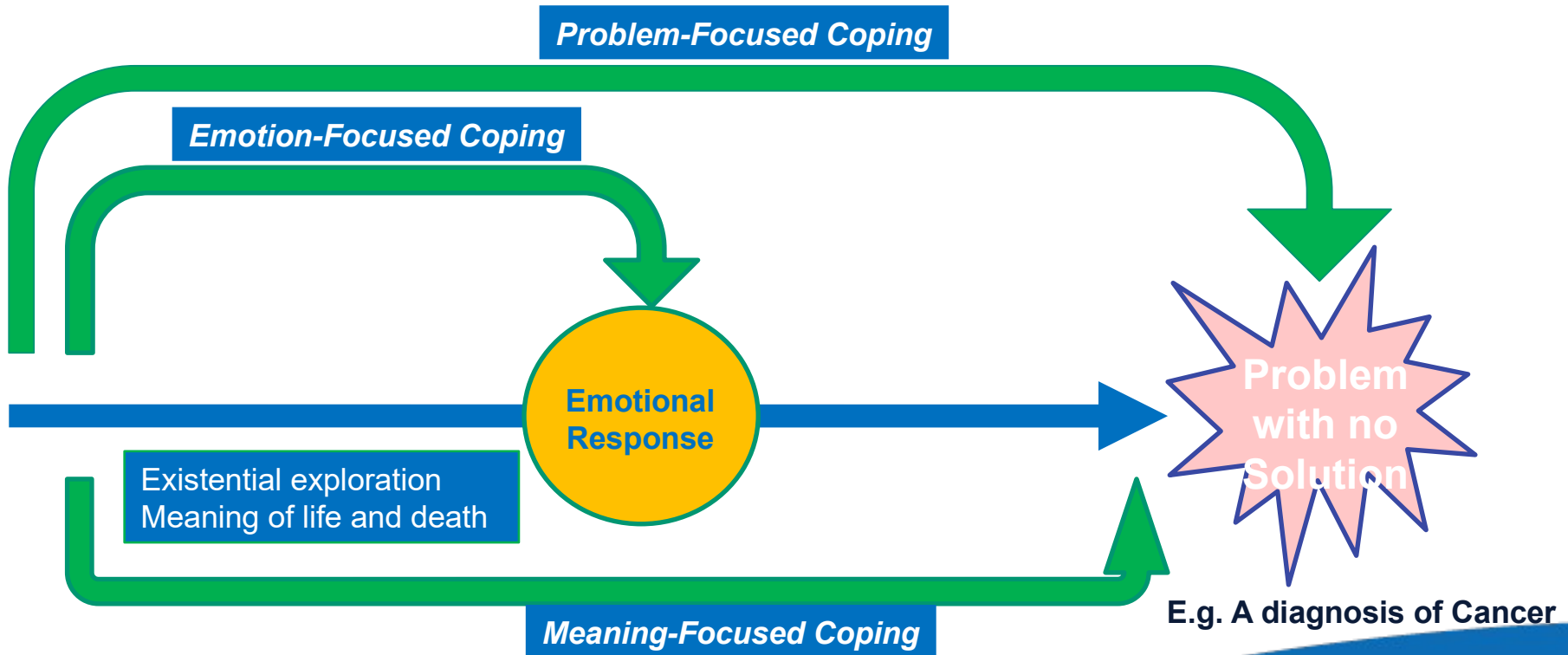


# Problem and Emotion-Focused Coping



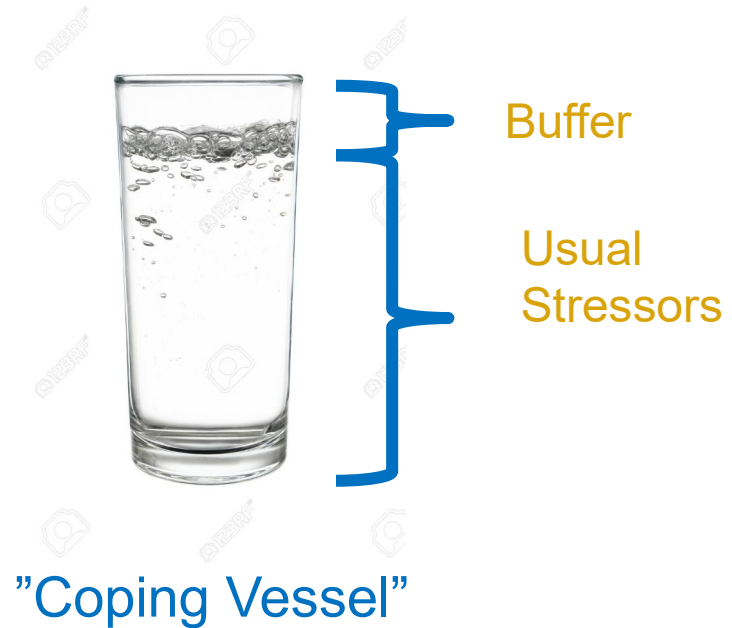
E.g. A diagnosis of Cancer

# Problem, Emotion and Meaning-Focused Coping



# Approaches to Coping with Active Surveillance

- 1) Making space for Active Surveillance anxiety
- 2) Identify your personal AS anxieties and organize according to controllability
- 3) Employ problem, emotion, and meaning-focused coping to Active Surveillance



# Making Space for Active Surveillance

- **Prioritize stressors**
  - **Being an attentive partner**
  - **Parenting or Grandparenting**
  - **Work Demands**
  - **COVID**
  - **Finances and taxes**
  - **Traveling abroad**
  - **Volunteering**
  - **Organizing a social occasion**



Buffer +  
Space for AS

Usual  
Stressors

”Coping Vessel”

# Making Space for Active Surveillance

- **Prioritize stressors**
- **Set more realistic expectations**
  - **Being an attentive partner**
  - **Parenting or Grandparenting**
  - **COVID**
  - **Finances and taxes**
  
  - **Work Demands**
  - **Traveling abroad**
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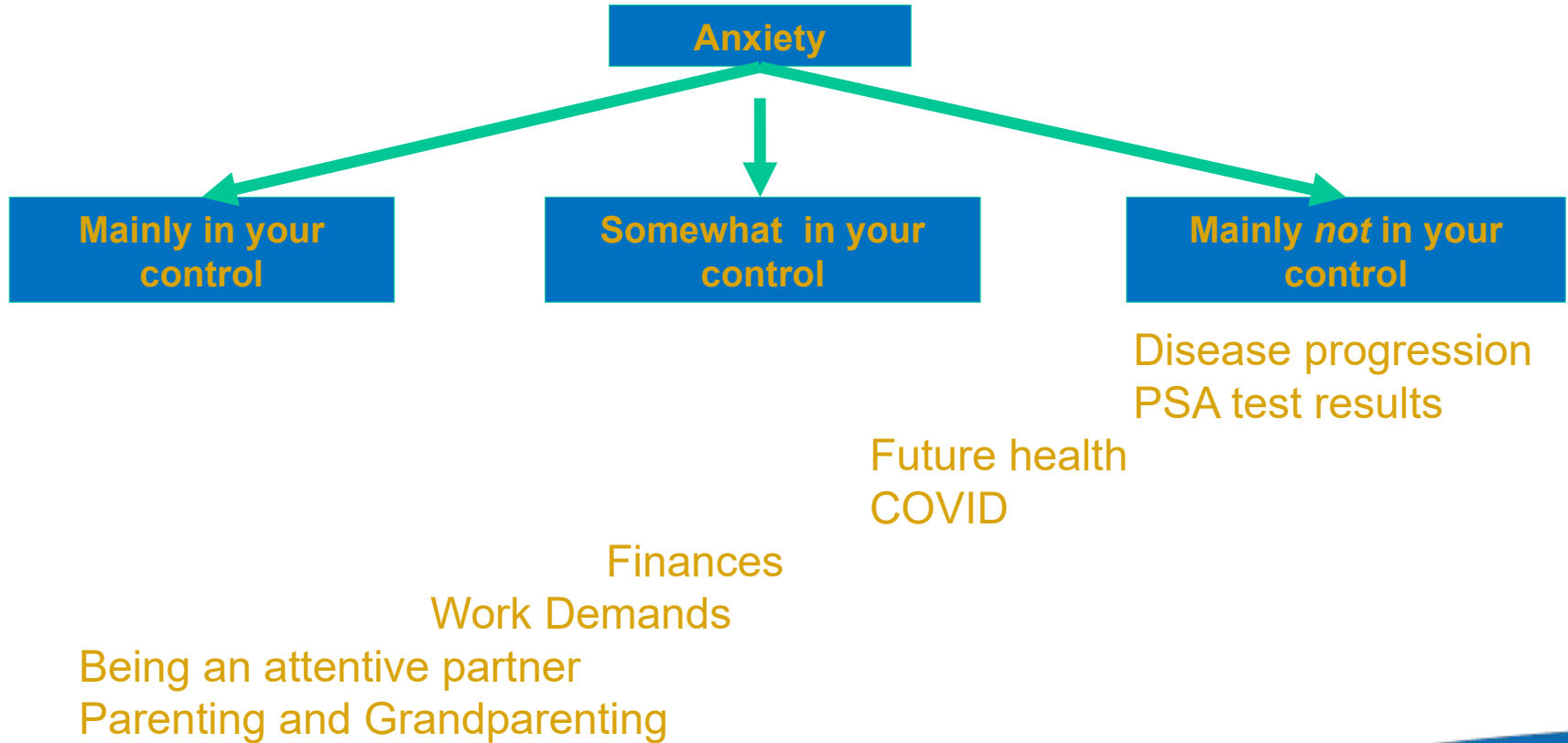
”Coping Vessel”



Buffer +  
Space for AS

Usual  
Stressors

# Controllable versus Not Controllable



# Problem-focused Coping and Active Surveillance

FOCUS IS ON WHAT IS IN OUR CONTROL

- *Research/Analysis = Trustworthy Knowledge = Well-Informed Risk Perception*
- **Self-care to prevent/manage anxiety**
  - Regulate overwork
  - Exercise and Yoga
  - Unplug
  - Progressive muscle relaxation and deep breathing exercises
  - Meditation and Mindfulness
  - Self-compassion Productivity – build a shed
- Access your **social support** system – you can rely on others too



# Emotion-Focused Coping and Active Surveillance

FOCUS IS ON WHAT IS NOT FULLY IN OUR CONTROL

- **Accepting and Adapting is not “Giving in”**
  - Tolerance of uncertainty
  - No amount of worry will affect the outcome
- Challenge yourself to **stay in the present.**
  - let go of yesterday’s regret and tomorrow’s uncertainty
  - We only have control over this moment.

# Emotion-Focused Coping & Active Surveillance

FOCUS IS ON WHAT IS NOT FULLY IN OUR CONTROL

- **Normalize** emotional responses to an extraordinary threat
  - Accept and normalize vulnerability > deny emotions
- **Cognitive Reappraisal-** Thoughts are not facts; many are simply beliefs
  - “Given statements” or “Automatic thoughts” can drive a car so they can certainly drive fear
- **Accepting and Adapting is not “Giving in!”**
  - Tolerance of uncertainty
  - No amount of worry will affect the outcome
- **Think of what you would tell a loved one to ease their worry**



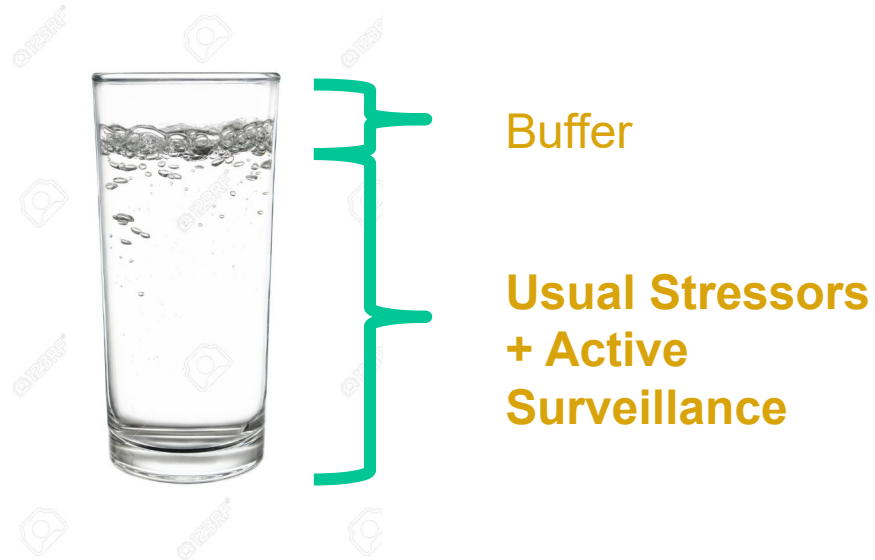
# Meaning-focused Coping to AS

FOCUS IS ON WHAT IS NOT FULLY IN OUR CONTROL

- Challenge yourself to **stay in the present**.
  - let go of yesterday's regret and tomorrow's uncertainty
  - We only have control over this moment.
- Reflect on the degree of control we all have over our health
- Reflect on facing mortality and the *meaning of life*:

*The relationships you have with the people you care about most*

# Successful Coping

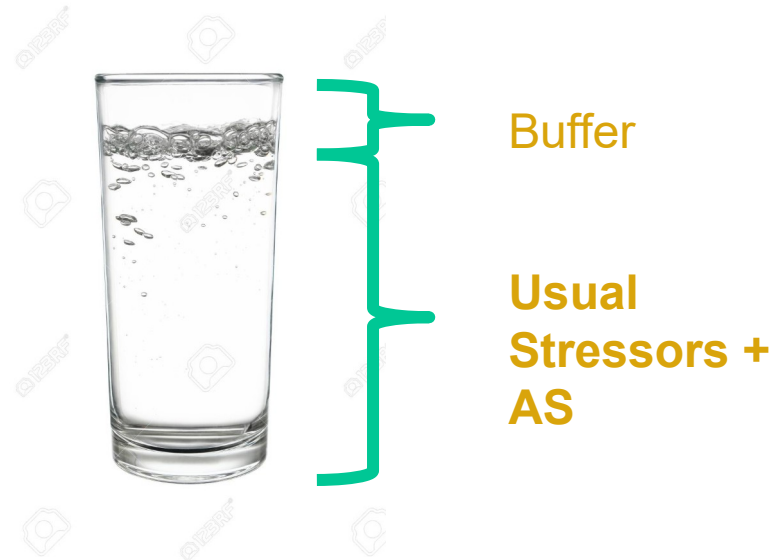


# And remember...

- If you don't take care of yourself, you can't take care of anyone else.
- **ANCan/Us Too AS Support Group...you are all in this together!**

“As we are liberated from our own fear,  
our presence automatically liberates  
others”

(Nelson Mandela)



## Community Support: ANCan/Us Too AS Support Group



THANK YOU