

Body, Mind, Self: an integration of MBSR & Chronic Disease Self-Management

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Disclosures

Presenters have no financial interest to disclose.

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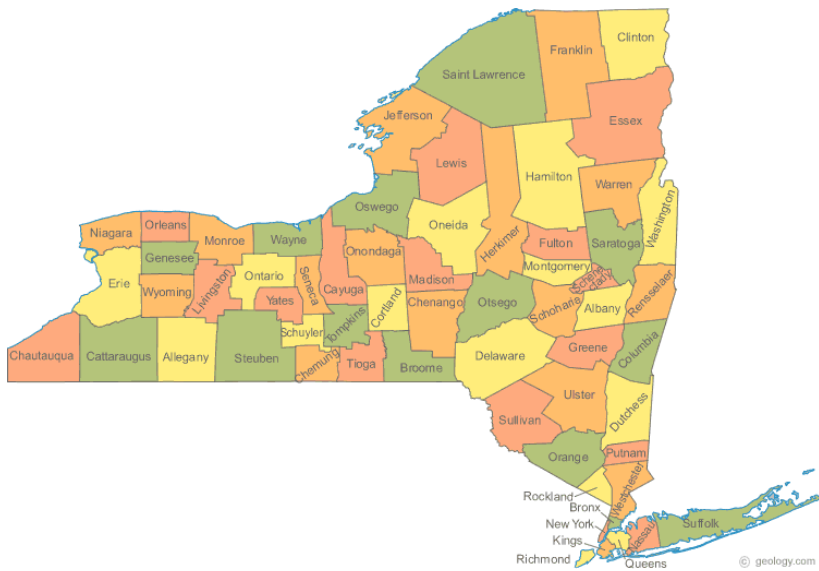


Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Describe how patient training in MBSR and CDSMP can positively impact health outcomes
2. Articulate the rationale for providing both interventions as components of patient self-management training
3. Discuss the key practices/tools taught in each intervention and practical strategies for program replication

Where in the world is Stony Brook?

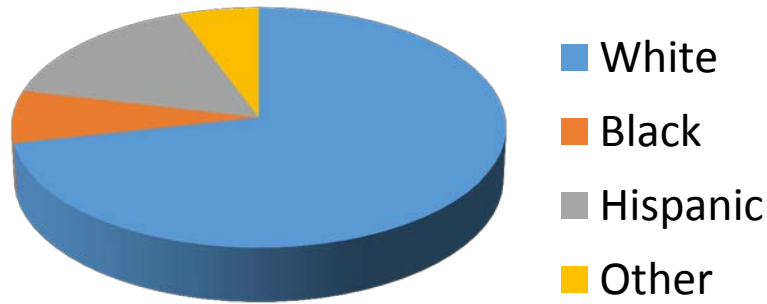


Suffolk County notable facts

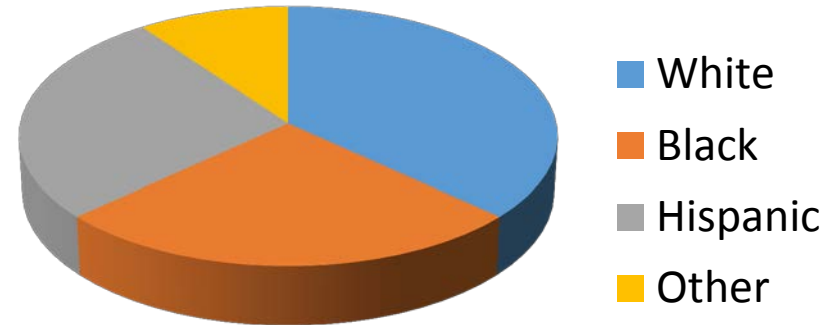
- 1.5 million population
- Cost of living among highest in the country, however,
- One of most segregated counties in US
- Pockets of poverty with majority Black/African American and/or Hispanic/Latino populations
- Minimal public transportation complicates service delivery
- More cases of HIV/AIDS than almost any other US suburb
- More opiate overdose deaths in 2015 than in any other county in New York State (including each of the boroughs of NYC)

HIV/AIDS in Suffolk County

Racial/ethnic makeup of overall population



Disproportionate impact of HIV/AIDS on communities of color (> 3,000 PLWHA)



Stony Brook University



- HIV program funded by Ryan White Part A, Part B, Part D and Part F (AETC); NYSDOH AIDS Institute; and clinical research grants
- Stony Brook serves > 800 PLWHA, Part D program services approximately 400 women, children and youth in Suffolk

Stony Brook's Part D program

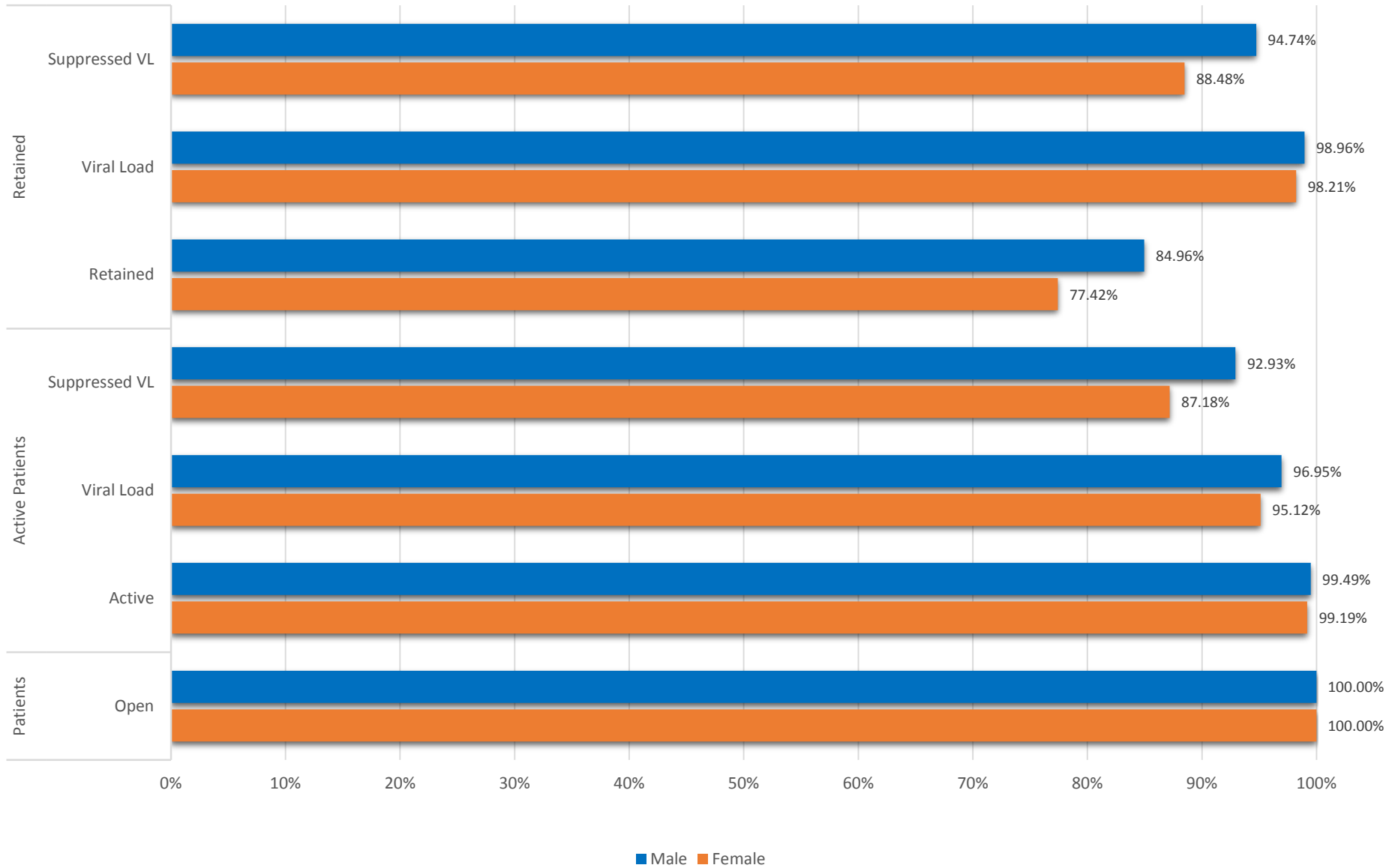
- Primary and specialty HIV medical care
- HIV testing and linkage to care
- Care coordination and retention
- Mental health services and neuropsychological assessments
- Nutritional assessments and education
- Respite and transportation
- Emergency food assistance
- Self-management program

Stony Brook HIV program 2015 care cascade definitions

- **Open Patients:** Patients (new, continuing, transferred in) with at least 1 visit in the past 24 months
- **Active Patients:** Open Patients with 1 visit in the past 12 months / Open Patients
- **Active Viral Load:** Active Patient with a viral load in the past 12 months / Active Patient
- **Active Suppressed Viral Load:** Active Patient with last viral load in past 12 months <200 / Active Patient with a viral load in past 12 months
- **Retained Patients:** Open Patient with 1 or more medical visits in each half of the year (Jan-June & July-Dec)/Active Patients with a medical visit in Jan- June 2015
- **Retained Viral Load:** Retained Patient with a viral load in the past 12 months / Retained Patient
- **Retained Suppressed Viral Load:** Retained Patient with last viral load in past 12 months <200 / Retained Patient with a viral load in past 12 months

* All data was obtained from manually reviewing patient's EMR for medical visits/notes and laboratories

Stony Brook 2015 Care Cascade by Gender



Why teach self-management?

Most of the time we spend managing our health conditions takes place outside of the doctor's office.

Self-management is what we do in between our health care visits.

Most of our clients are living with multiple chronic conditions –
and HIV is often the easiest one to manage.

Self-management program model

- Stanford's Chronic Disease Self-Management Program (CDSMP) – *6 week series of 2 ½ hour classes once a week*
- (interim while staff being trained - Cicatelli Associates Self-Management training – *3 day retreat*)
- Mindfulness Based Stress Reduction (MBSR) in English and Spanish – *8 week series of 2 hour classes once a week plus 6 hour silent retreat*
- Future plans include teaching CDSMP in Spanish (Tomando Control de su Salud) and Positive Self-Management Program as well as developing a monthly Sustaining Mindfulness program

What is CDSMP?

- Developed in 1991 at Stanford University (collaborative research project with Northern CA Kaiser Permanente)
- More than 50 studies found that people who participate in CDSMP have fewer symptoms, better quality of life, exercise more and utilize health care less
- Despite the fact that it is not directly addressed by the program, studies found statistically significant improvements in adherence
- Research shows that those who attend at least 4 sessions benefit as much as those who attend all 6

Assumptions underlying CDSMP

- People with mental and physical chronic conditions have similar concerns and problems
- People with chronic conditions must deal not only with their diseases, but also with the impact these have on their lives and emotions
- Trained peers with chronic conditions can facilitate CDSMP as effectively, if not more effectively, than health professionals
- The process or the way CDSMP is taught is as important, if not more important, than the subject matter that is taught

Major skills in CDSMP

- Action planning
- Problem solving
- Decision making

People learn best by being taught a little bit, having a chance to try things out, getting feedback, and building on what they have learned.



What is Mindfulness-Based Stress Reduction (MBSR)?

MBSR is a method of using yoga and meditation to cultivate awareness and reduce stress. It is about waking up, being fully alive and being present for each moment of our lives.

Simply put, it is about paying attention.

What are the goals of MBSR?

- Challenge

This program challenges participants to practice present moment awareness, deep relaxation, and gentle movement.

- Discovery

Through the use of these techniques, a person learns to discover and observe his/her reactions to life's stressors and to choose how to respond.

Practice, practice, practice.

- Practice

With practice, one can apply these skills to everyday situations and connect more fully with one's self, loved ones and the life one is living.



Research in HIV+ populations

- Since 1979 research on effects of MBSR in populations coping with cancer, fibromyalgia, asthma, high blood pressure, GI disorders, HIV as well as depression, bipolar disorder, social phobia etc.
- Some examples: MBSR on CD4 lymphocyte counts in stressed HIV+ adults
- MBSR for reducing ART symptoms
- Research is ongoing and the program is being introduced into several hospitals and clinics all over the US
- Is an integral part of health care treatment at Center for Mindfulness at University of Massachusetts

Why do we believe in teaching both?

Although the principles that guide MBSR and CDSMP are different, the goal of each intervention is to enable participants to develop sustainable practices and become fully engaged in self-management.

Different skills and techniques resonate with each person so by teaching both classes we increase opportunities for our clients to identify and practice strategies that work for them.

Topics covered in CDSMP

- Overview of self-management and chronic health conditions
- Using your mind to manage symptoms
- Getting a good night's sleep
- Making an action plan
- Feedback and problem-solving
- Dealing with difficult emotions
- Physical activity and exercise
- Preventing falls
- Making decisions

Topics in CDSMP - continued

- Pain and fatigue management
- Better breathing
- Healthy eating
- Communication skills
- Medication usage
- Making informed treatment decisions
- Dealing with depression
- Working with your health care professional and organization
- Weight management
- Future plans

Nuts and bolts of MBSR

- MBSR is structured into 8 sessions and a one-day retreat (6 hours of mindfulness practice) between sessions 6 and 7 and instruction on 3 formal techniques: mindfulness meditation, body scanning and simple yoga practices.
- Each session is conducted once weekly for 2 hours.
- The following attitudinal characteristics are reinforced throughout the entire program:
 - ❖ *Patience*
 - ❖ *Trust*
 - ❖ *Beginner's mind*
 - ❖ *Acceptance*
 - ❖ *Non-striving*
 - ❖ *Letting go*



Mindful Inquiry

At the end of each practice participants will be asked to respond voluntarily to a few questions about their individual experience:

- What did you notice? What were you aware of? What showed up?
- How might this be different from how you normally pay attention?
- How might this reduce stress? How might this contribute to a sense of well-being?



Sample CDSMP activity

Parts of an Action Plan

1. Something YOU want or decide to do
2. Achievable
3. Action-specific
4. Answer the questions:
 What? How much? When? How often?
5. Confidence level of 7 or more



The power of Breathing.

- Assume a comfortable posture of sitting. Keeping the spine straight and letting your shoulders drop.
- Allow your eyes to close it that's comfortable for you.
- Allow your attention to fall on your belly, feeling your belly rise or expand gently as you breathe in, and fall or recede as you breathe out. There is no need to deliberately change the rhythm of your breathing.
- Notice the different physical sensations in your body as you breathe, "being with" each in breath for its full duration and "being with" each outbreath, as if you are riding on waves of your own breathing.
- Each time you "notice" that your mind has wandered off the breath, gently bring your attention back to the belly and to the sensations associated with the breath coming in and going out.
- As you breathe you may hear sounds of someone coughing or sneezing, allow yourself to hear the sounds around you, while you focus on your breath.

Self-management program activities to date

Between October 2014 and June 2016, we have offered:

6 cycles of MBSR (including 1 specifically for program staff and 1 in Spanish)

2 three-day self-management retreats

2 cycles of CDSMP

Self-management program participants

A total of 60 people have attended one or more of the programs including:

38 HIV+ women and youth from Suffolk County

2 HIV affected women

4 HIV+ men

1 HIV+ woman from outside of Suffolk

15 staff (including HIV infected/affected)



Program participants continued

Of the Part D program clients participating in the program:

- 66% attempted SM training and 96% of those completed - attending at least 4 of 6 sessions of CDSMP or an entire 3-day retreat
- 84% attempted MBSR and 75% of those completed - attending at least 6 of 9 sessions
- 50% attempted both and 84% of those completed both

Program participant demographics

Part D Self-Management program participants:

92% women

8% youth

45% black

37% white

16% Hispanic

2% Asian

Overall Part D program clients:

89% women

11% children/youth

36% black

35% white

27% Hispanic

8% Asian/Native Amer/> 1 race

Perceived Stress Scale

The Perceived Stress Scale (PSS 10) is a validated psychological instrument for measuring the perception of stress.

Questions ask about feelings and thoughts in the last month and respondents are asked to indicate how often they felt a certain way.

Our program participants were asked to complete the PSS 10 at the beginning of the first MBSR class and the completion of the last class.

Obtaining “clean” data was more challenging than expected.

Perceived Stress Scale Norms

Norm Table for PSS 10

	Mean	S.D.
Male	12.1	5.9
Female	13.7	6.6
Black	14.7	7.2
White	12.8	6.2
Hispanic	14.0	6.9
Other	14.1	5.0

Data gathered on 2,387 respondents in US (L. Harris Poll), also included mean scores for different age groups

Participants pre and post MBSR

Average pre

Average post

Average change

All 19 clients with “clean” data

21.42

16.16

↓ 5.26

17 clients who completed MBSR (6 of 9 sessions)

22.29

16.18

↓ 6.12

3 clients who attended all 9 sessions

28

10

↓ 18

13 staff who participated

15.3

12.8

↓ 2.5

Outcome evaluation plan

To compare rates of retention and viral load suppression before and after participation in Stony Brook's Self-Management program for three groups:

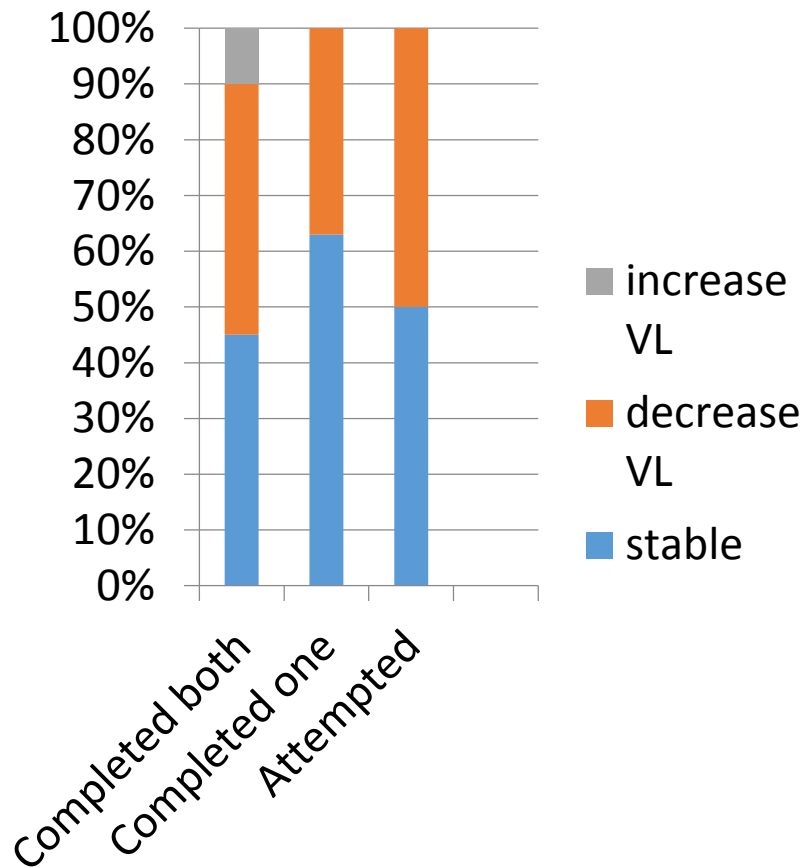
- Those completing both CDSMP and MBSR
- Those participating in one or both (but not completing both)
- Those who did not participate in either class

Reality check

Although we targeted clients who were not well retained in care and/or not virally suppressed for enrollment in self-management trainings, most of those who have actually participated to date were retained and had undetectable viral loads prior to their participation (and have remained so).

Also, before we can make meaningful comparisons between outcomes for those who have participated in self-management training and those who have not, we will need to have a greater % of our clients participate.

Health outcomes



Important to note:

- Improvements were generally modest
- Stable does not always mean undetectable
- Only a small % of clients have participated to date



Qualitative examples of successes

- Less need for ongoing crisis intervention, greater reliance on self
- Less fearful of attending follow up appointments especially for procedures hence increased compliance, hence better health outcomes
- Immediately available internal toolbox
- Awareness of self care
- Feeling of empowerment
- Different attitude to difficult situations

Participant feedback

Question: How did these trainings help if at all?

“ It helped me to pay attention to things around me and to focus on the moment. When I get anxious, I remember to breathe. I can do that anywhere.”

“ When I was told I was diabetic, I was in denial. After the practice, I realized I have to accept that it is here and I cannot run from it.”

“ I learned to meet people where they are and to listen to someone else.”



Participant feedback - continued

“Oh, I’m so looking forward to doing it again!”

“We have difficult lives. I don’t get bent out of shape when things arise. Instead of running and taking flight, I have learned to call someone, talk it out, instead of sitting worrying about it.”

“It helped me center myself and get my thoughts together. I’m actually on my way to have a LEEP done at this very moment. It reminds me to breathe like right now on my way to the doctor’s.”

Participant feedback - continued

“Of course it helped!.. to focus...to handle situations differently...It brings you back...instead of always rushing, to stay a little. It was a challenge but you have to be open-minded. It’s about self care you know.”

“I just wanted to tell you that your programs are life-saving for me...I’m a whole new me!”

Lessons learned

- Getting patient and staff buy-in is time consuming but crucial for success
- Don't underestimate the ongoing challenges of recruiting participants, meeting logistics, client support and staffing
- Challenge of defining new roles specific to the trainings (for both facilitators and participants)
- Benefits for patient retention are to be expected but benefits for recruiting peer workers is a pleasant bonus

Lessons learned - continued

- Finding funding may be easier than you expect
- Length of time needed to get staff trained makes self-sufficiency a long-term goal
- If using supplemental funding to build your program, sustainability plans are key
- Plans for obtaining health outcome data need to be realistic



Take home MBSR

- It's all about practice.
- Practice the breathing exercise for 15 minutes every day at a convenient time, even if you don't feel like it, for 1 week.
- Or if you feel like you don't have the time, tune into your breathing at different times during the day.
- Notice your body sensations as you breathe.

Take home CDSMP

Make an action plan for the next week (something YOU want to do)

Keep it small and something you are confident that you can achieve

Make it action-specific (What? How much? When? How often?)

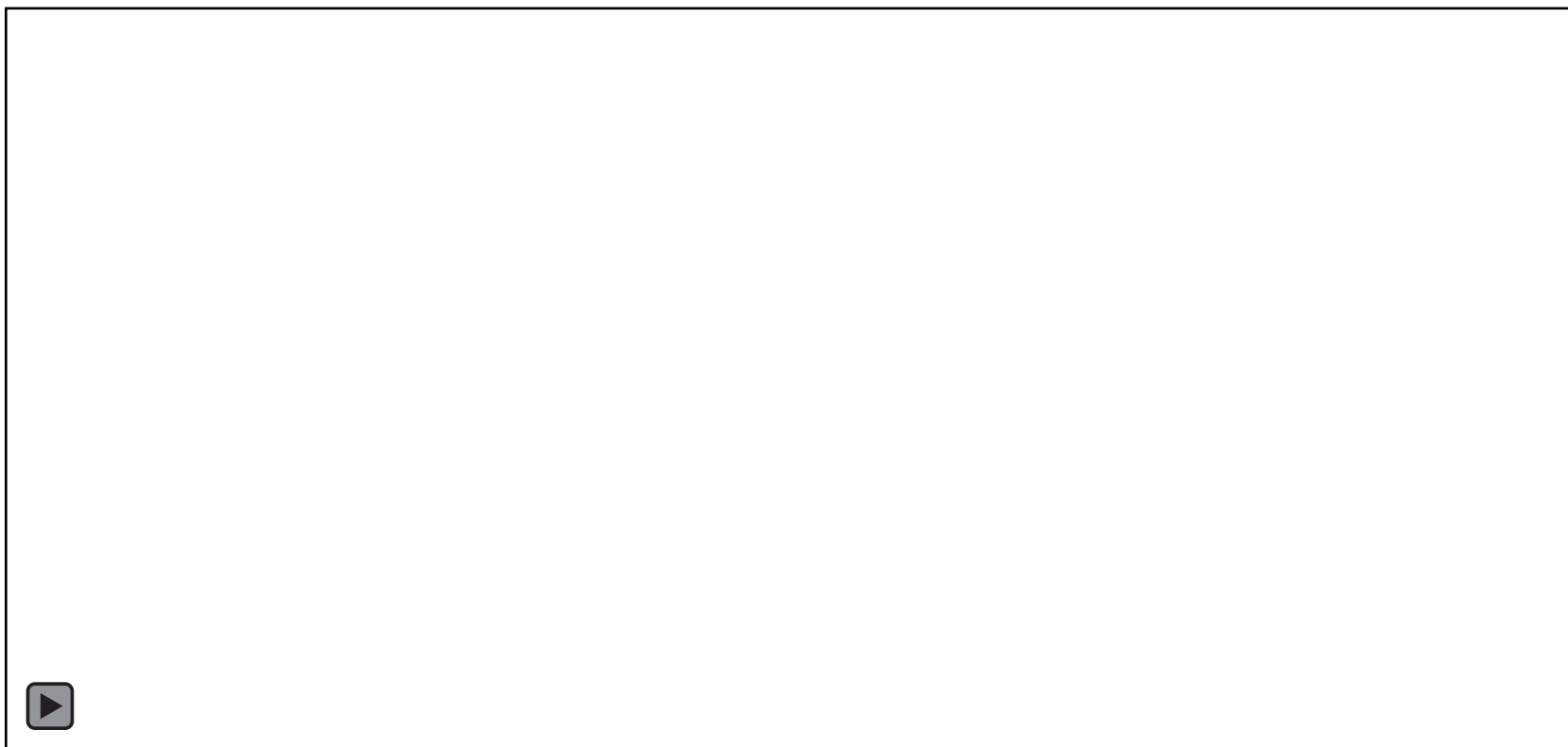
Tell a friend your plan and ask them to check in to see if you accomplished it

(or better yet, pick something you can do together)

Repeat

Justin Brewer: A simple way to break a bad habit

(filmed November 2015)



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To obtain training:

For CDSMP:

Stanford University Patient Education Research Center
patienteducation.stanford.edu

For MBSR:

University of Massachusetts Center for Mindfulness
umassmed.edu/cfm/training/MBSR-Teacher-Education

or

UC San Diego Center for Mindfulness
mbpti.org



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