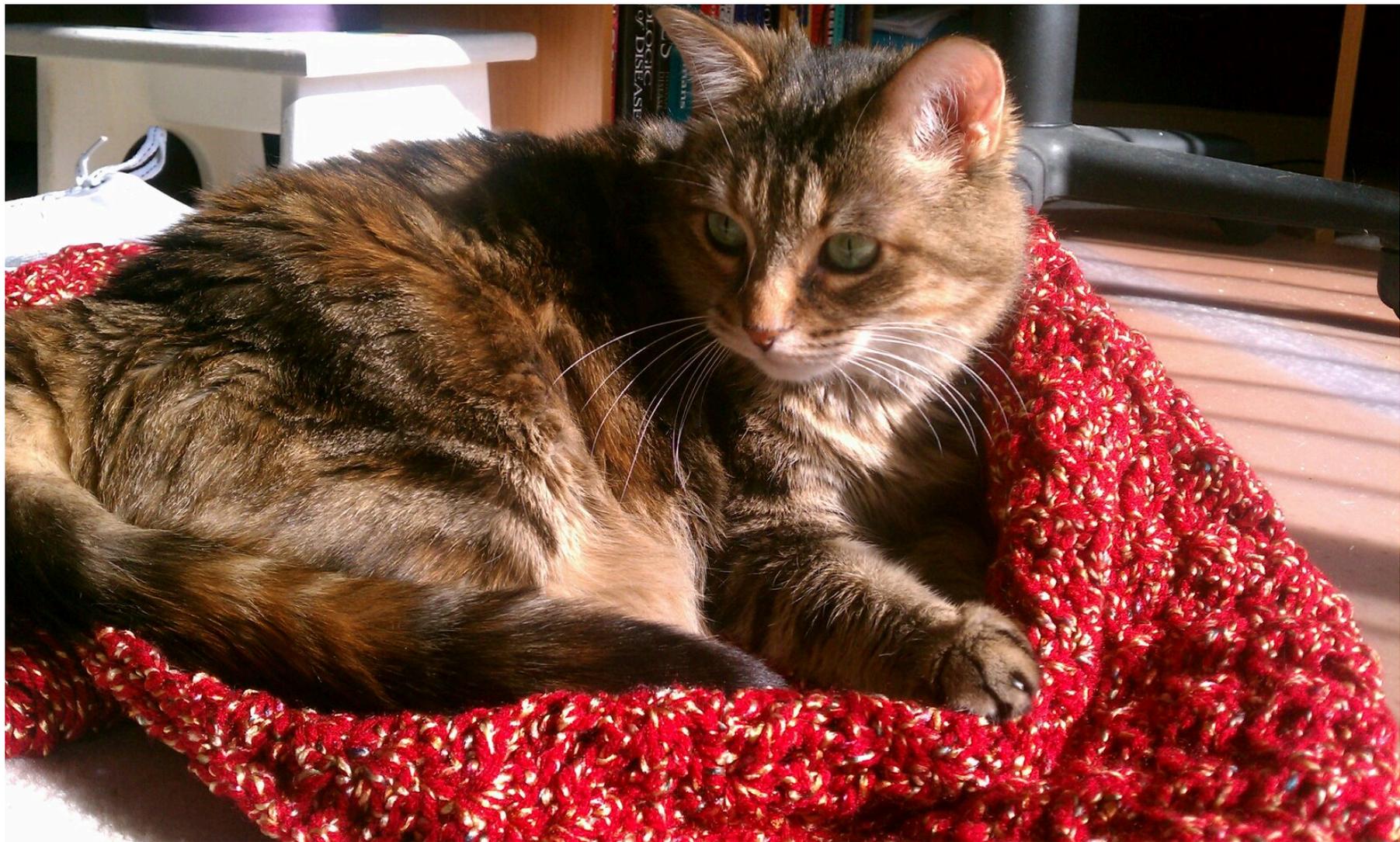


**REALITIES OF RECOVERY  
NEDS CONFERENCE 2016**

Carrie Arnold

# OUTLINE

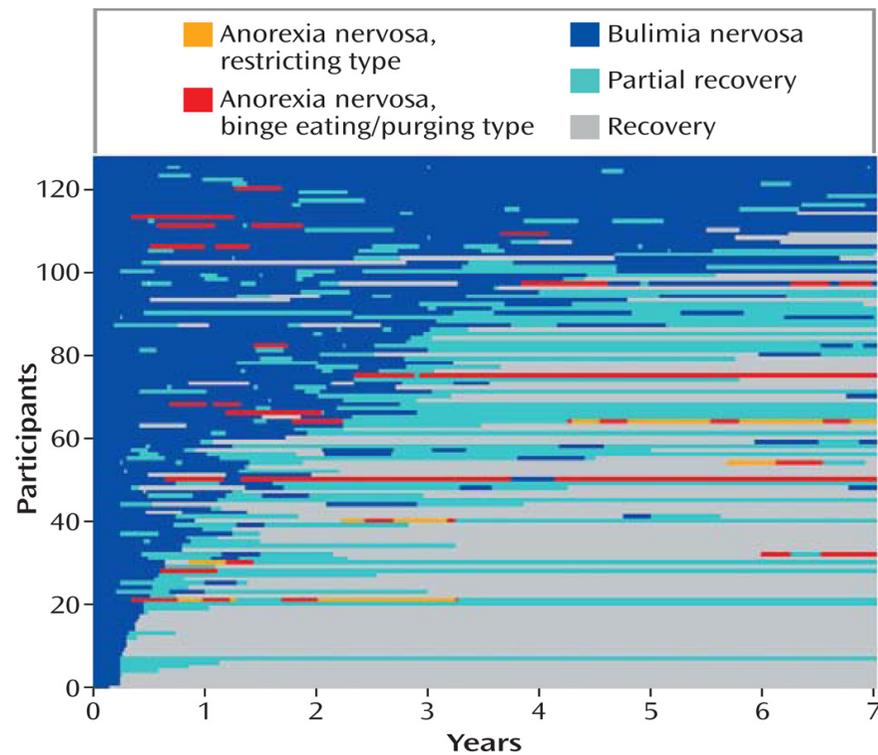
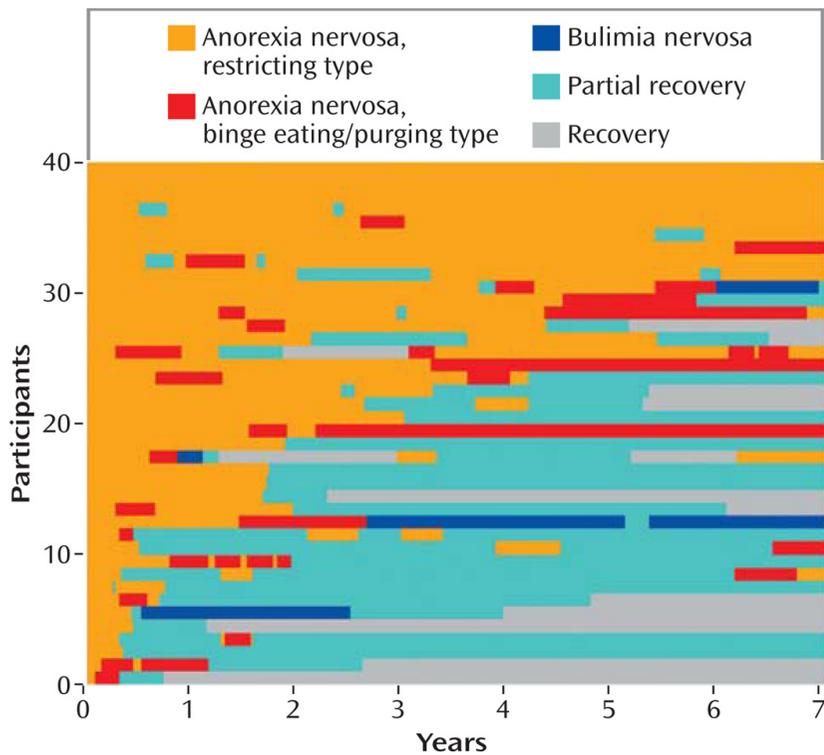
- What is recovery?
- What do people say about the process of getting there?
- What are the major roadblocks to recovery?
- What happens after an eating disorder?



# WHAT IS RECOVERY?

- How do researchers define recovery from an eating disorder?
- Is this process more accurately described as recovery or remission?

# COURSE OF EATING DISORDERS



Eddy et al, (2008). *Am J Psychiatry*. PMID: 18198267

# RELAPSE IS COMMON

- After hospital treatment for anorexia, between 35-40% of individuals who are weight restored will relapse back into the full-blown disorder within 18 months
  - Longer follow-up periods (2.5 years) revealed 57% relapse rate
  - Targeted relapse prevention reduces full relapse to 11%, with 70% having partial relapse
- Relapse rates lower but still significant for BN, BED, OSFED
- Relapse after remission linked to social difficulties and body image distress

# DEFINITIONS OF RECOVERY/REMISSION

- All definitions of AN recovery involve normalization of body weight, resumption of menstruation (where appropriate)
  - Carter et al. (2012): BMI >20, less than one binge/purge episode for two weeks
  - Lock & LeGrange FBT studies of AN: 95+% IBW and EDE scores within one standard deviation of community norms
    - Also found that weight gain predicted psychological recovery

# DEFINITIONS OF RECOVERY/REMISSION

- For BN, definitions include cessation of binge/purge behaviors
  - Grillo et al. (2007): no more than subthreshold symptoms for 8 consecutive weeks creating less than moderate impairment in functioning
  - Olmstead, Kaplan, & Rockert (2005): “Relapse rates at 19 months ranged from 21% to 55% depending on the definitions of remission and relapse applied.”
- Many progress from AN/BN diagnoses to OSFED/EDNOS diagnoses over time
  - Some suggest this reflects partial recovery, but still diagnosable eating disorder

# WHY DEFINITIONS MATTER

- Eating disorders tend to wax and wane over time
- From a study on BN recovery/remission (Field et al., 1997):  
“When defining remission as at least 4 weeks of being asymptomatic, a quarter of the women relapsed within 11 weeks. By 37 weeks, only 49% of the women remained asymptomatic (95% CI, 41–61). ***The probability of relapse was substantial for approximately a year after a woman ceased to binge and purge.***”

# WHAT DO THESE TELL US?

- Only about clinical samples in specialized eating disorder clinics
  - Probably not representative of most people with eating disorders
- Need for better, more standardized definitions of recovery
  - Simply no longer meeting criteria for AN, BN, or BED does not mean recovery—you can still be very ill without a threshold diagnosis
  - Definitions need to be more holistic, not just looking at ED behaviors, but also at psychosocial, occupational, familial functioning

# POPULAR RECOVERY NARRATIVES

- “An eating disorder is something that you will deal with forever.”

OR

- “I’m fully recovered. I love my body. I will never relapse.”

# REAL RECOVERY IS ON A CONTINUUM

**Full-blown illness**

**Full recovery**



# POPULAR IMAGES OF RECOVERY



- Young
- White
- Thin
- Female

**TABLE 3** Ranking of Most Important Criteria for Recovery

		Criteria for recovery	Patients	Therapists
1	A5	Does not take laxatives	100%	98%
2	E2	Is able to express her emotions (verbal)	98%	94%
3	B1	Does not feel too fat	97%	64%
4	D2	Self esteem is no longer dependent on weight	97%	92%
5	D4	Does not punish herself after a meal	97%	86%
6	D8	Has a realistic image of herself	97%	88%
7	A1	Eats three meals a day	95%	96%
8	A3	Has no binges	95%	76%
9	A4	Does not vomit after dinner	95%	100%
10	A6	Does not use diuretics	95%	90%
11	B5	Is not obsessed by food and weight	95%	64%
12	E3	Is able to express her emotions (nonverbal)	95%	76%
13	E4	Is able to handle negative emotions	95%	90%
14	F3	Is not isolated	95%	92%
15	B4	Feels no need to slim excessively	93%	92%
16	A8	Does not exercise excessively	92%	92%
17	A7	Does not use slimming pills	90%	80%
18	B3	Accepts her appearance	90%	80%
19	E9	Is in touch with her own feelings	90%	90%
20	B2	Has a positive experience of the body	85%	68%
21	D1	Has adequate self-esteem	85%	80%
22	E5	Is able to handle positive emotions	84%	82%
23	E1	Is not depressed	83%	76%
24	A2	Amount of calories is normal	83%	72%
25	C7	Heartbeat is normal	83%	58%
26	E8	Is able to handle conflicts	83%	78%
27	C15	Sleeps normally	83%	38%
28	F2	Is able to make contact with others	83%	82%
29	F4	Has some friends	83%	74%
30	D6	Is not extremely perfectionistic	80%	68%
31	E7	Dares to express a different opinion	80%	70%



**NOOOOO!**

**I'M FAT!**



**He finally found a box big enough  
to accommodate his ego**

Albert is not having the best day.



# WHAT DOES IT MEAN TO RECOVER?

1. to accept myself and my body (76%)
2. not to use food to resolve problems and not to let food dominate life (76%)
3. to feel that life has a purpose to oneself and to others (38%)
4. to have contact with emotions and the courage to express them (33%)
5. to have less anxiety and depression (29%)
6. to fulfil own potential and not just to conform to expectations from others (20%)
7. to have a good social functioning (13%)

Pettersen & Rosenvinge, , 2002

# DIFFERENT WAY OF THINKING ABOUT RECOVERY

- Recovery is a **set of skills** that need to be **learned** and **practiced**
  - Sometimes these skills were never learned
  - Other times they've been forgotten
- Need to start with the basics and build on them over time
  - More intensive support at first, then transitioning to more independence

# FOOD-RELATED RECOVERY SKILLS

- Eating regular meals and snacks
- How to eat for weight maintenance (post-nutritional rehabilitation)
- Food prep and cooking
  - How to put together a basic meal
- Meal planning
- Tolerating having food around
- Body/weight acceptance

# OTHER RECOVERY SKILLS

- Asking others for help
- “Tattling” on the eating disorder
- Self-care
  - Adequate sleep
  - Not over-working yourself
  - Self-soothing
- Developing new hobbies
- Creating personal/professional career goals

# PHYSICAL ROADBLOCKS TO RECOVERY

- Lingerin<sup>g</sup> physical consequences from the eating disorder
  - Osteoporosis
  - Gastroparesis
  - Irritable bowel syndrome
- Difficulties with hunger/fullness cues
- Hypermetabolism

# INTERPERSONAL ROADBLOCKS TO RECOVERY

- Lack of supportive relationships
- Difficulties with emotional vulnerability
- Misconceptions about eating disorders and recovery among friends and family
- Family members “walking on eggshells” and/or enabling disordered behaviors to keep the peace



**Get off the table!**

**YOU'RE NOT MY REAL MOM!!!**

# PSYCHOLOGICAL ROADBLOCKS TO RECOVERY

- EDs tend to have an adaptive function
  - Decrease feelings of depression/anxiety
  - Weight loss can temporarily improve self-esteem
- “Who am I without my eating disorder?”
- Social anxiety
- Hard to form new relationships

# SYSTEMIC ROADBLOCKS TO RECOVERY

- Lack of access to care
- Cultural misunderstandings
  - “I wish I had anorexia.”
  - “Why don’t you just put your fork down?”
  - “People of your race/gender/age/etc don’t get eating disorders.”
- Need for ongoing, long-term support that often isn’t available
- Normalization of dieting and other eating disordered behaviors

# ROADBLOCK DETOUR

- Roadblocks make the eating disorder continue to be the default option in life
- Need to rebuild your environment to make recovery the go-to option
  - Support
  - Accountability
  - Structure

# LIFE AFTER RECOVERY

- Possibility of relapse never goes away completely
  - Tendency towards relapse can vary
  - Some need ongoing weight monitoring and psychological support to stay well
- Many have co-occurring mental health conditions that need treatment
  - Depression, anxiety, PTSD, BPD, etc

# LONG-TERM PROGNOSIS

- Most people with eating disorders do ultimately get well, or at least significantly improve
- Having a history of an ED still affects long-term quality of life (Mitchison et al., 2013)
  - Strongest effects were on social functioning due to shape and weight concerns, and ongoing binge eating
- Lingering body image concerns predict relapse after symptom remission (Keel et al., 2005)

# LINGERING QUESTIONS

- Much in this area that we don't know:
  - Who will continue to struggle with maintaining recovery?
  - What type of support is needed?
  - What predicts relapse after long-term recovery?

