

THE PSYCHOLOGY OF COELIAC DISEASE AND GFD ADHERENCE

Dr. Kirby Sainsbury
PhD, D Psych (Clinical)
Newcastle University

Outline

- Psychology: what and why?
- The building blocks of behaviour change
- Explaining the ‘intention-behaviour gap’
- Initiation vs. maintenance
- What can you do?
- Children and adolescents



What is psychology?



- The science of thoughts, emotions, and behaviour
- Health psychology
 - *Adjustment to illness*
 - *Adherence to treatment/medical recommendations*
 - *Health behaviour change*
 - *Attitudes, beliefs, behaviour*
- Clinical psychology
 - *Mental illness*
 - *Symptoms*
 - *Treatment and prevention*
 - *Emotions, distress, wellbeing*

Why psychology?

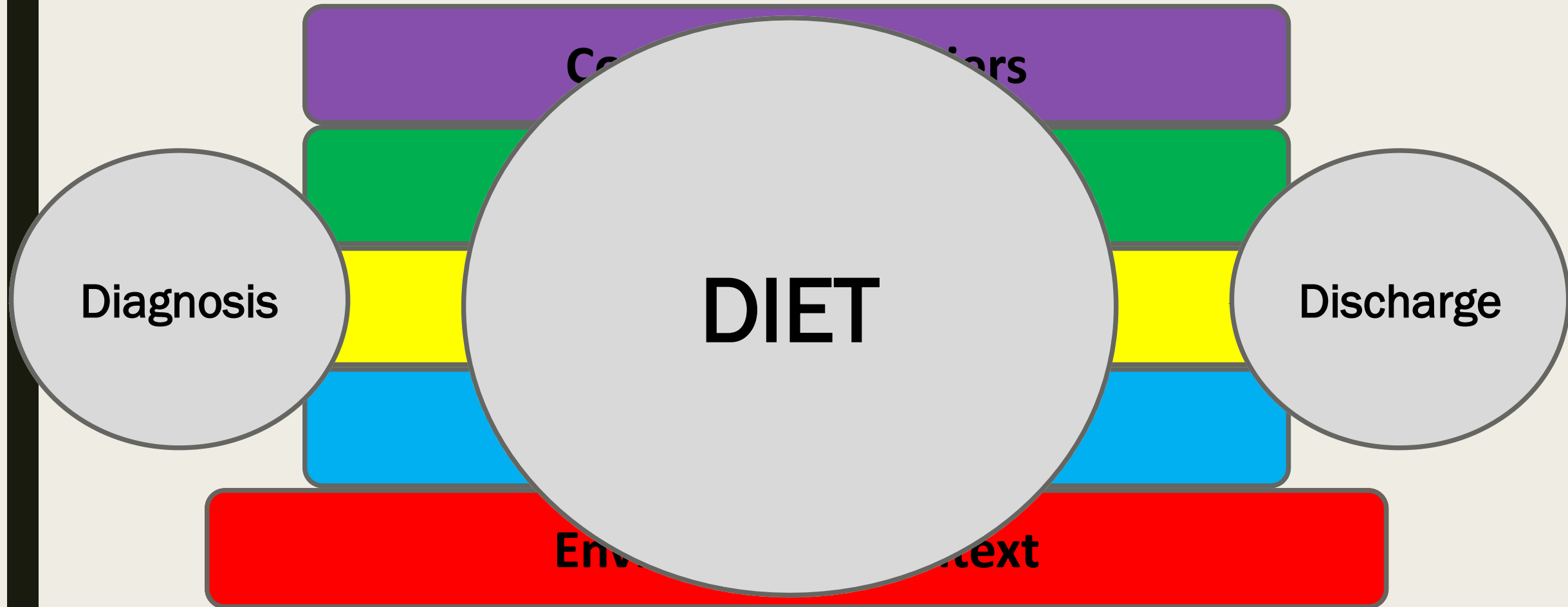


- Rates of strict adherence are inadequate
- Knowledge-behaviour gap
- Patient behaviour is the single most important factor that determines clinical outcome/remission in CD
- Need to understand the *modifiable* patient factors associated with poor adherence → design interventions (formal and/or clinical practice) to improve adherence

Building blocks of behaviour change

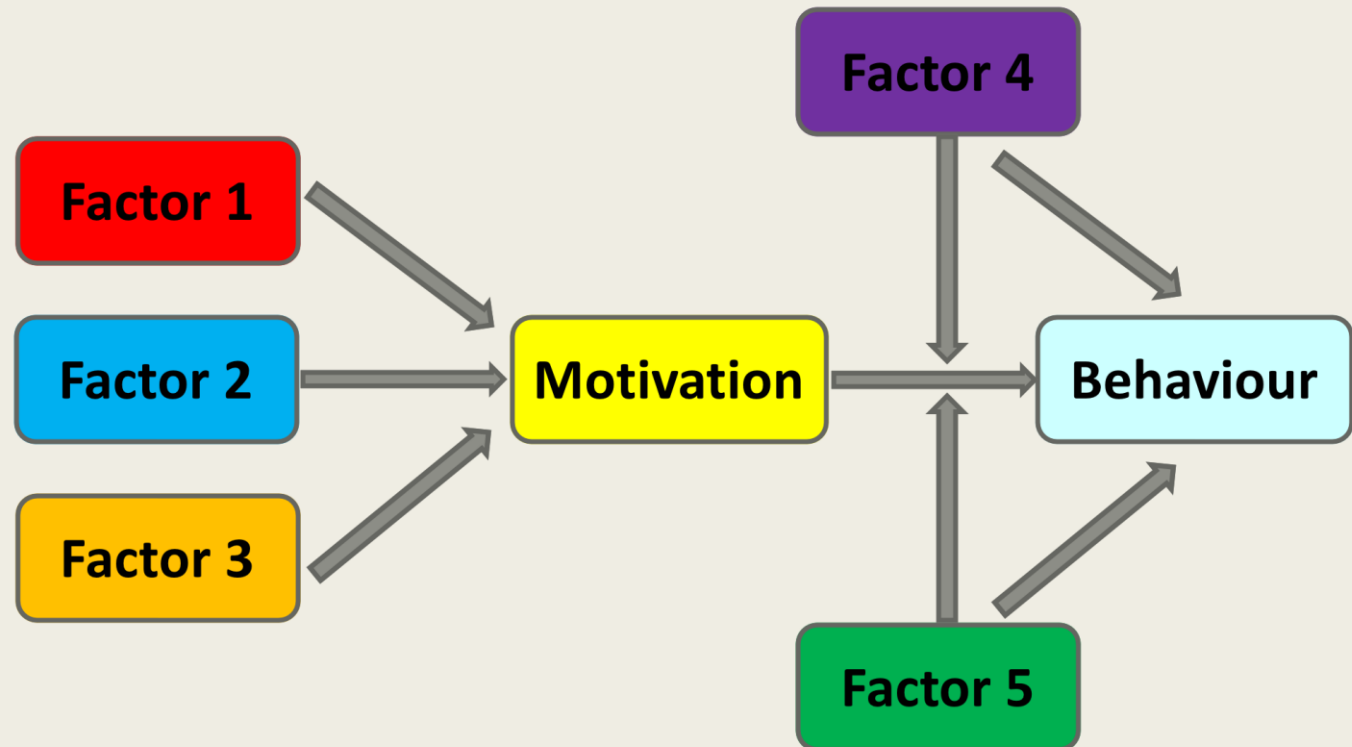
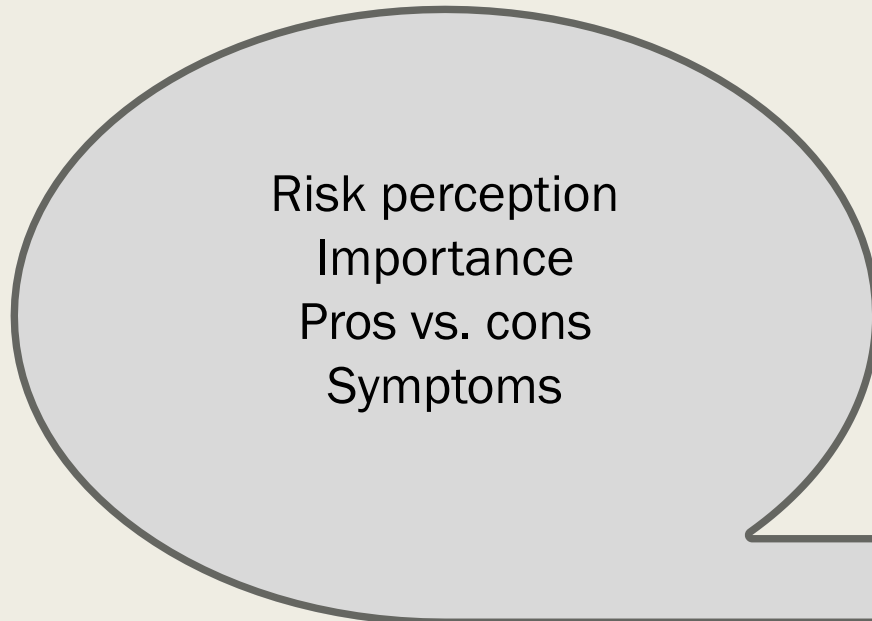
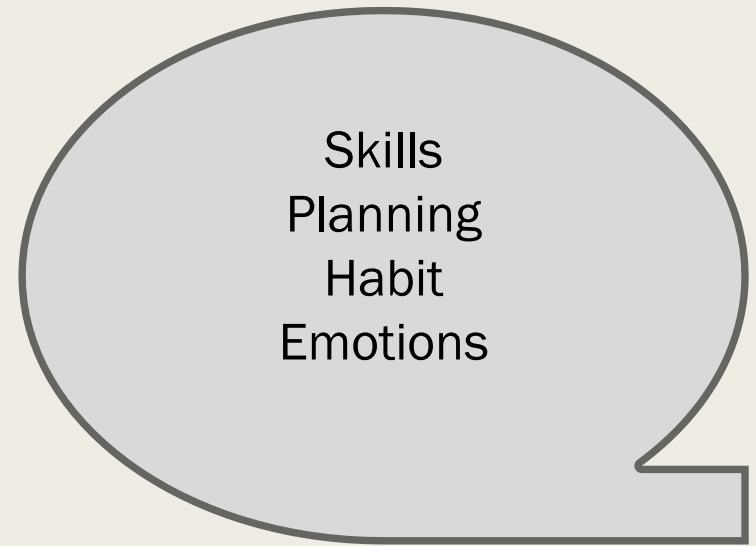


Building blocks of behaviour change



Theory

- Blue print for intervention efforts
- Why did/didn't it work?



The intention-behaviour gap

- Why do some people with coeliac disease fail to adhere strictly to a GFD despite having positive intentions to do so?

- Depressive symptoms
- Coping strategies
- Emotion regulation
- Confidence



Sainsbury et al. (2013). Gluten free diet adherence in coeliac disease: The role of psychological symptoms in bridging the intention-behaviour gap.

Depressive symptoms



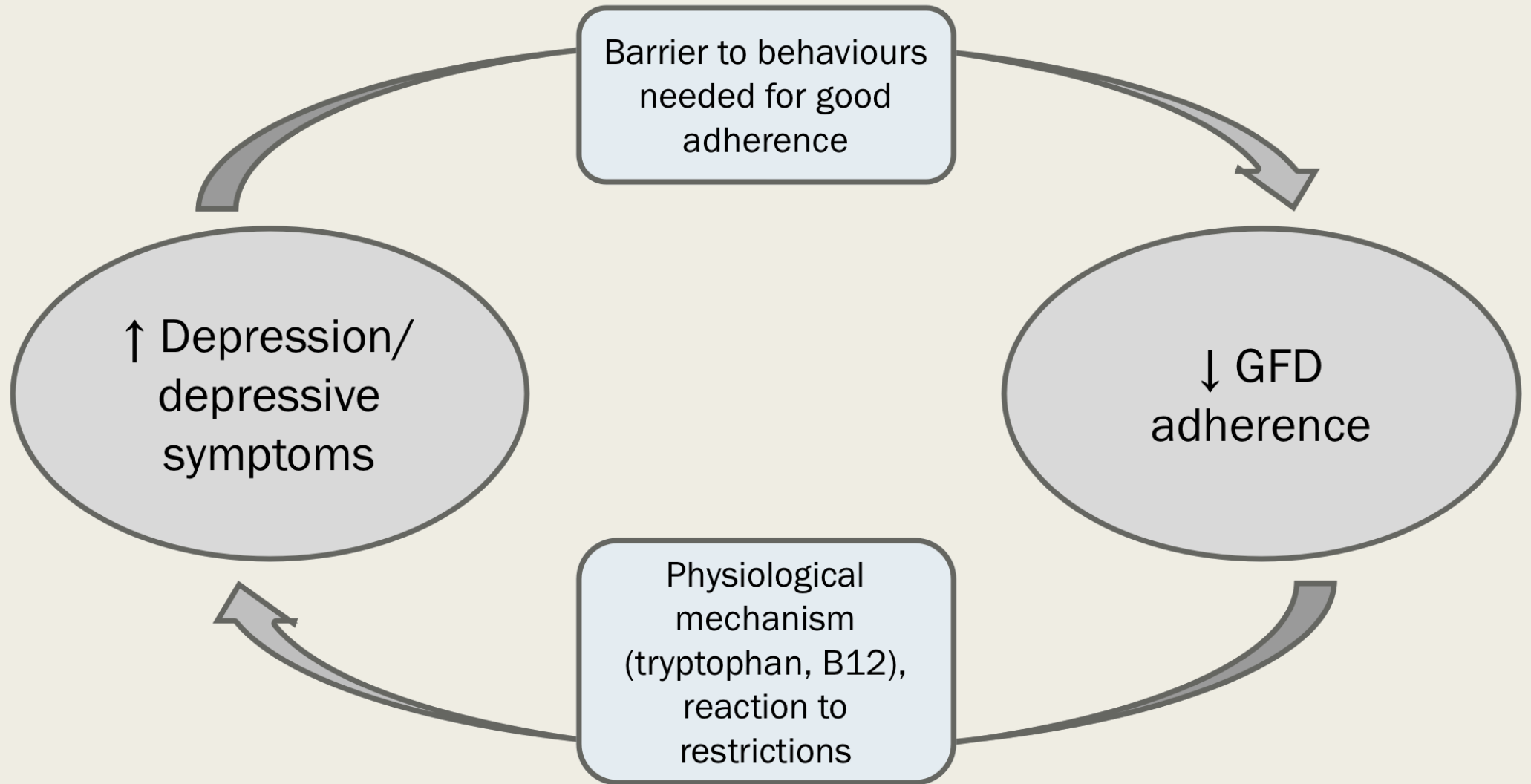
- Depressive symptoms are more common in coeliac disease than healthy controls (= other chronic illnesses)
- Depressive symptoms explained some of the intention-behaviour gap
 - Positive intentions: inadequate adherence > strict GFD
- Higher depressive symptoms associated with poorer GFD adherence (medium effect size: $r = .40$)

Ludvigsson et al. (2007). Coeliac disease and risk of mood disorders: A general population-based cohort study.

Sainsbury, Mullan, & Sharpe (2013). GFD adherence in coeliac disease: The role of psychological symptoms in bridging the intention-behaviour gap.

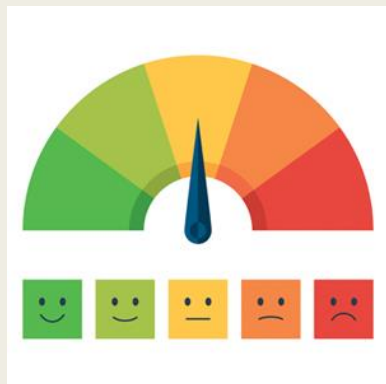
Sainsbury & Marques (2018). The relationship between GFD adherence and depressive symptoms in adults with coeliac disease: A systematic review with meta-analysis.

Smith & Gerdes (2012). Meta-analysis on anxiety and depression in adult celiac disease.



Coping strategies & emotion regulation

- Better GFD adherence associated with:
 - ↑ task-oriented coping (e.g., problem solving)
 - ↑ acceptance, reappraisal (i.e., thinking differently)
 - ↓ emotion-oriented coping (e.g., getting upset/frustrated)
 - ↓ maladaptive coping (e.g., distraction, self-blame, suppression)
- Only the maladaptive strategies differentiated intenders with good vs. inadequate adherence
- Coping related to depressive symptoms



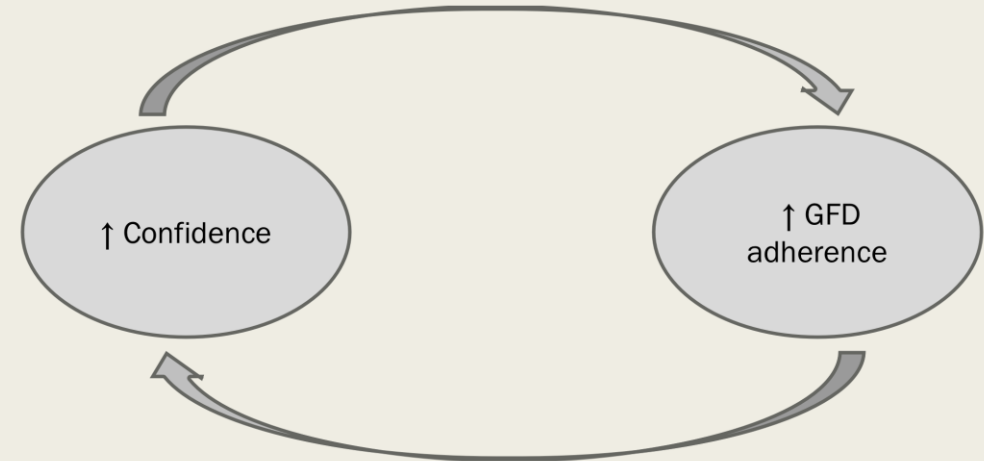
Kerwsell & Strodl (2015). Emotion and its regulation predicts gluten free diet adherence in adults with coeliac disease.

Sainsbury & Mullan (2011). Measuring beliefs about gluten free diet adherence in adult coeliac disease using the theory of planned behaviour.

Sainsbury, Mullan, & Sharpe (2013). Reduced quality of life in coeliac disease is more strongly associated with depression than gastrointestinal symptoms.

Confidence

- Better GFD adherence associated with:
 - General confidence for adherence
 - Confidence for the specific behaviours
 - Confidence to balance adherence with other goals/priorities
 - Perceptions of behavioural control (vs. actual behavioural control)
 - Perceptions of difficulty



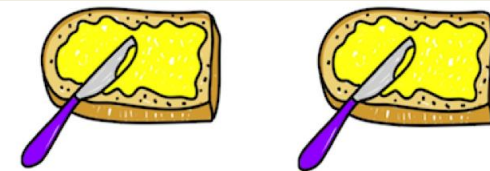
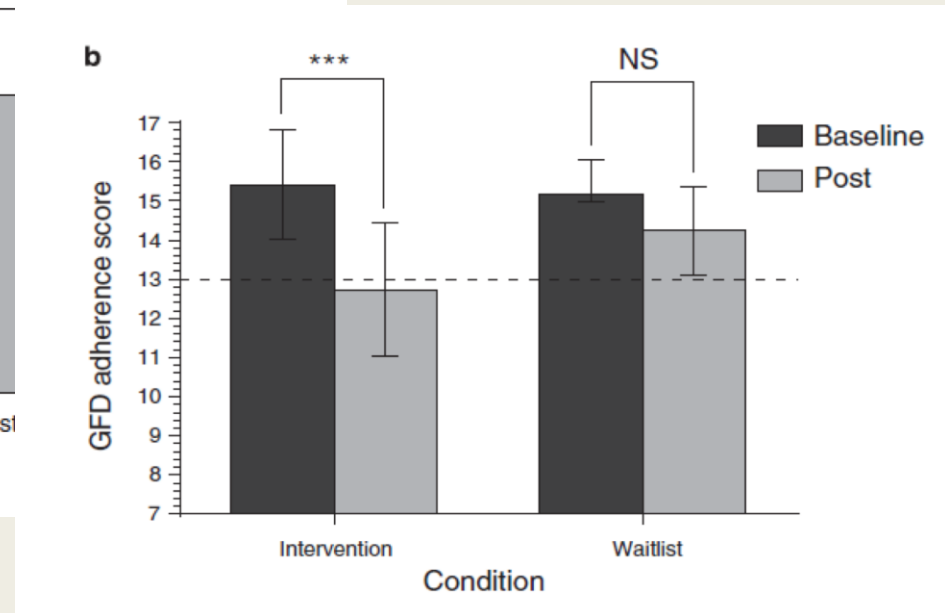
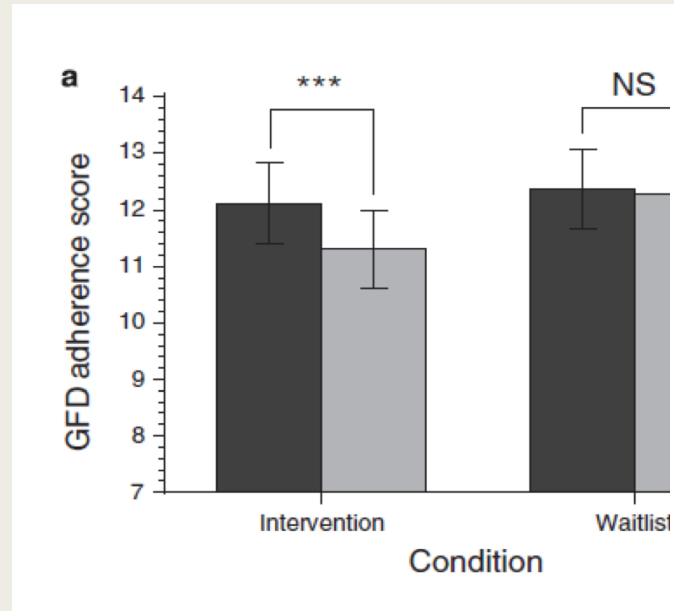
Dowd et al. (2016). Prediction of adherence to a gluten-free diet using protection motivation theory among adults with coeliac disease.

Hall et al. (2013). Intentional and inadvertent non-adherence in adult coeliac disease: A cross-sectional survey.

Sainsbury & Mullan (2011). Measuring beliefs about gluten free diet adherence in adult coeliac disease using the theory of planned behaviour.

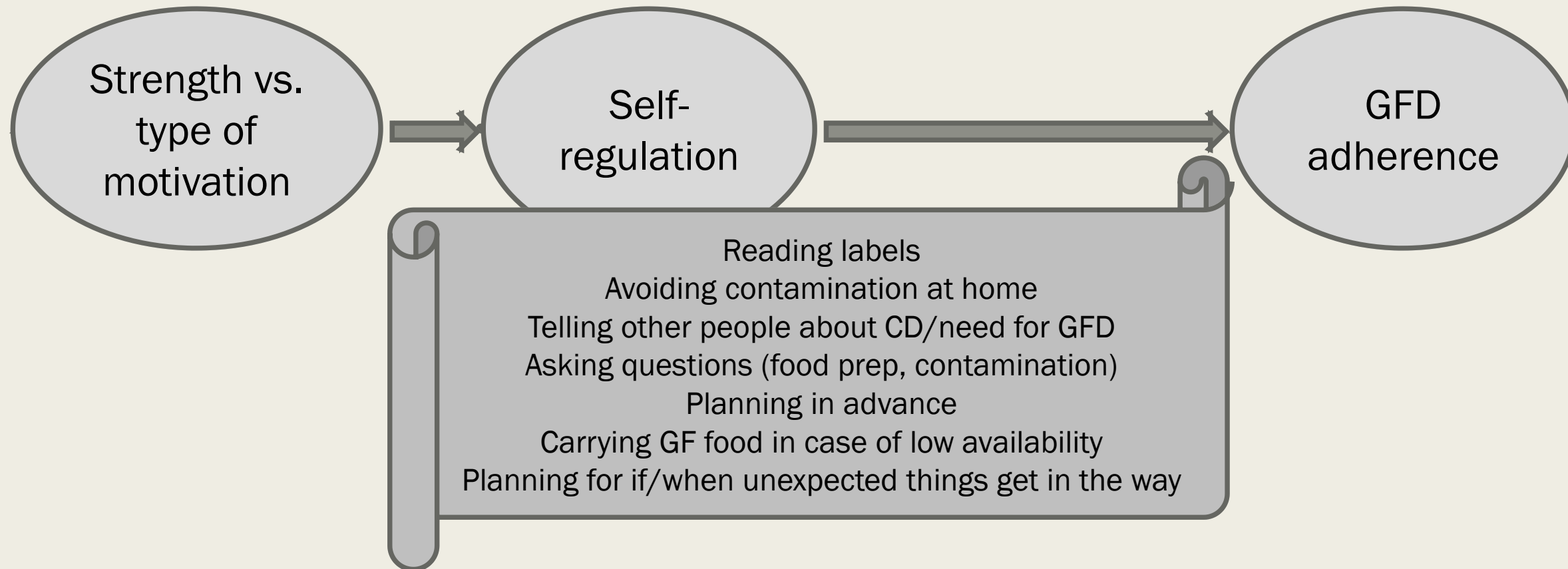
An intervention to improve GFD adherence

- Motivation
- Confidence
- Beliefs/attitudes
- Knowledge
- Coping:
 - problem solving, communication, reframing, achieving balance between GFD and other areas of life

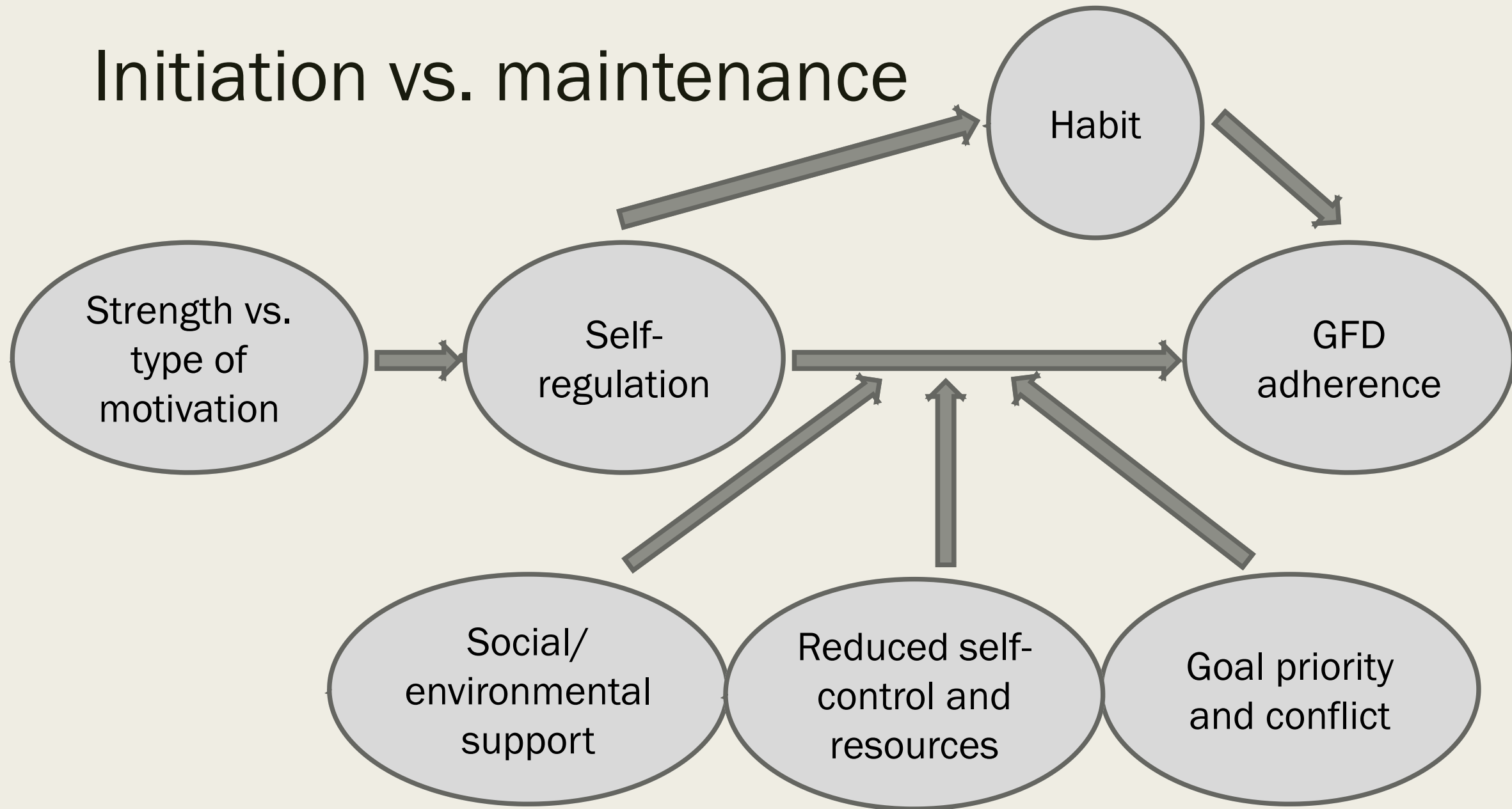


Bread n' Butter... Gluten Free of Course!

Initiation vs. maintenance



Initiation vs. maintenance



The role of the ‘maintenance constructs’ in GFD adherence

- Cross-sectional survey in Australia and New Zealand
- N = 5573
- Measures:
 - GFD adherence (coeliac dietary adherence test)
 - Psychological distress
 - Intention, perceived behavioural control
 - Maintenance constructs



Results

- ✓ Type of motivation
- ✓ Resources
- ✓ Self-regulation
- ✓ Habit
- ✓ Goal priority and conflict
- ✓ Support
- ✓ Intention
- ✓ Perceived control
- ✓ Distress



Results: type of motivation



- Enjoyment of behaviour
- Consistency with values
- Part of who I am
- Increased energy
- To feel emotionally well

- Avoid pre-diagnosis symptoms
- Avoid symptoms post-diagnosis with gluten
- To feel physically well

- To avoid long-term health problems

- *Other people expect me to*
- *My GP/health professional told me to*
- *I would feel guilty if I didn't*

Results: type of motivation



- Enjoyment of behaviour
- Consistency with values
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- **Avoid pre-diagnosis symptoms**
- **Avoid symptoms post-diagnosis with gluten**
- **To feel physically well**

- **To avoid long-term health problems**

- *Other people expect me to*
- *My GP/health professional told me to*
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Results: psychological resources



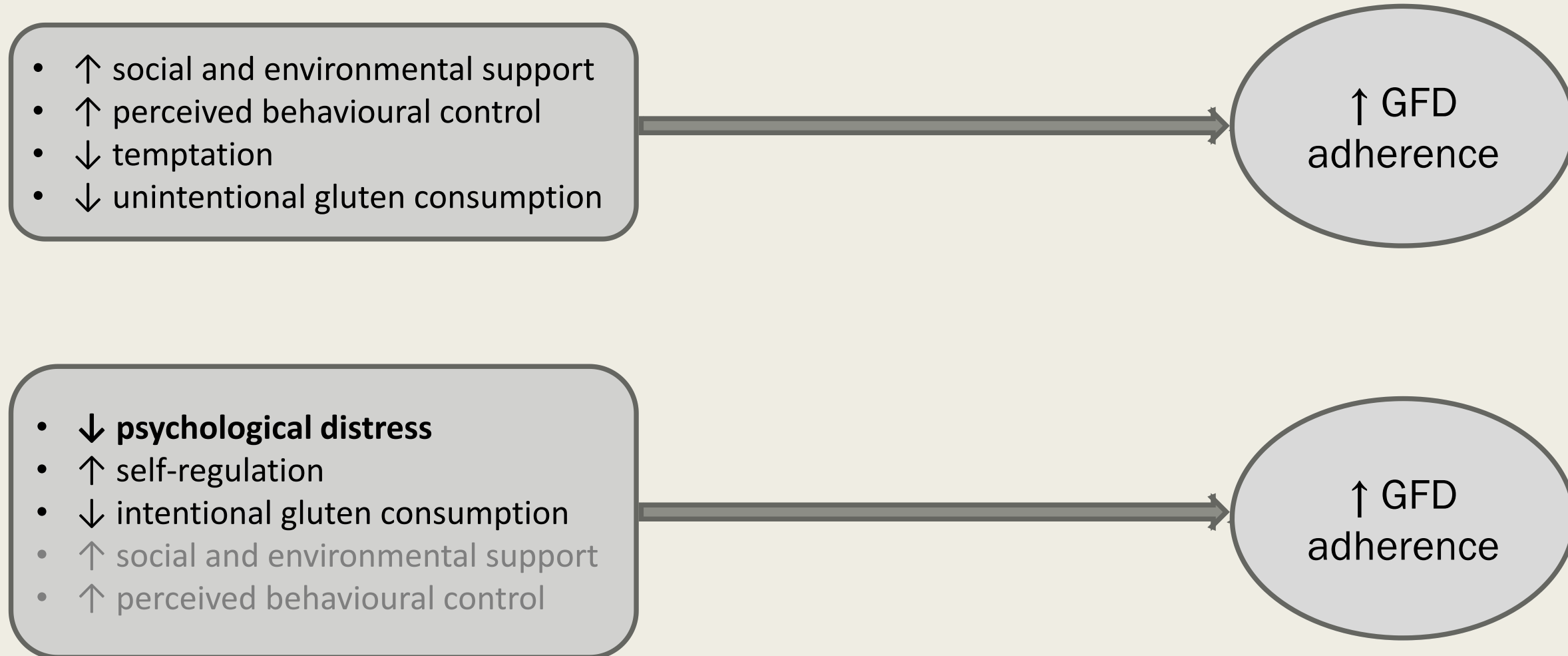
- Temptation: 68-81% never felt tempted
- Intentional gluten consumption: 88-94% never
- Less careful → potential unintentional gluten consumption: 70-89% never

- Busy/limited time
- Break from usual routine

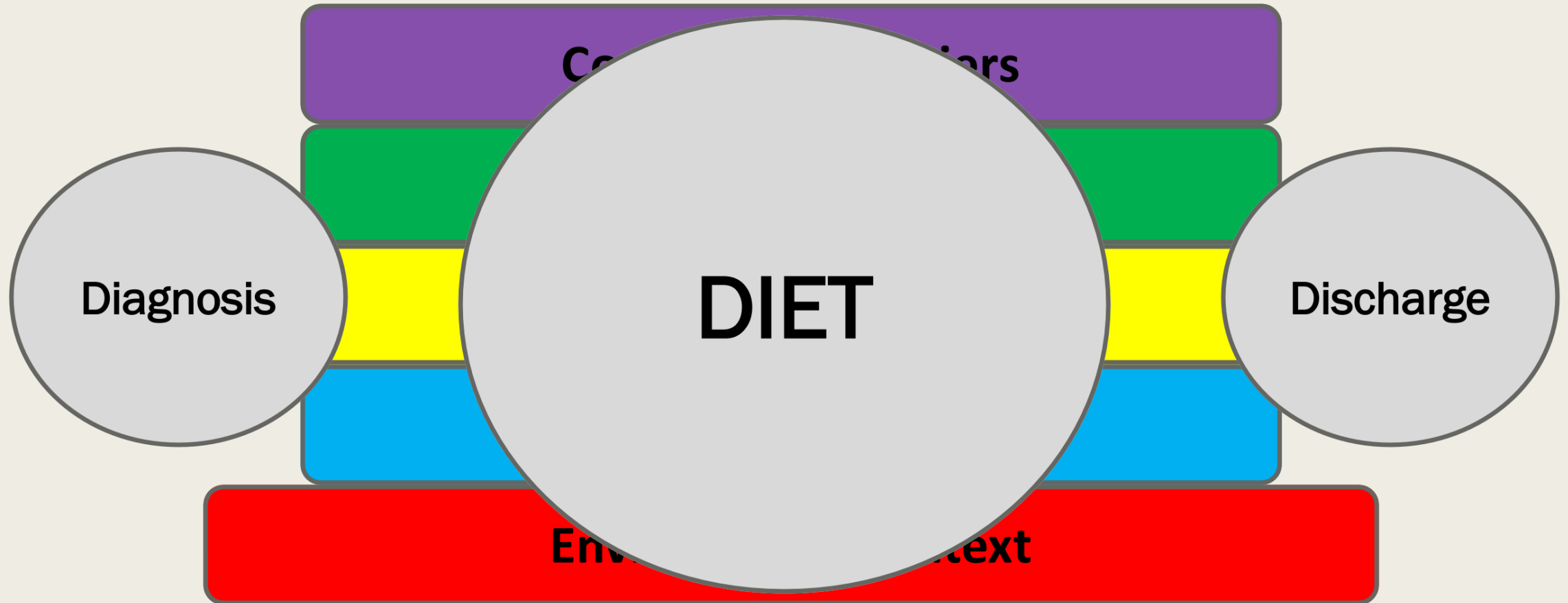
- Stressed
- Upset/down
- Emotionally exhausted

- Feeling physically unwell
- Unable to see any positive effect of the GFD
- Bored
- Tired
- Low energy
- Unmotivated

Results: predicting GFD adherence



What can you do?



What can you do?

Encourage development of future-focused, internal motivations for adherence

Enlist and/or mobilise social support

Normalise/validate difficulties and need for effort at start → easier with time (habit)

Prompt patient to identify risky situations when self-control and resources are likely to be low (different routine, busy, stressed) → plan

Identify any conflicting priorities and plan/problem solve ways to integrate GFD

Identify depressive symptoms → referral to psychologist

Children and adolescents



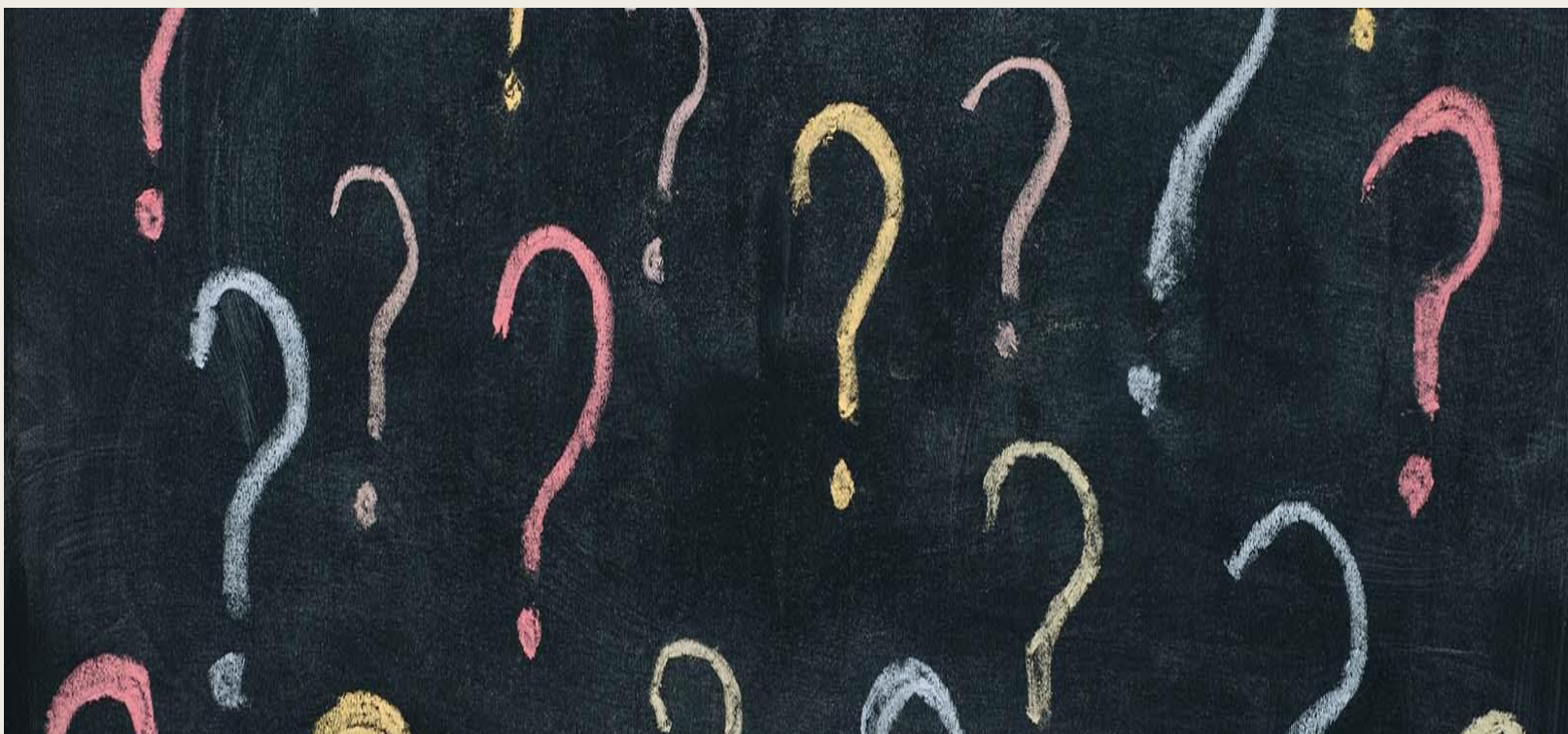
- Mood and behavioural changes may be suggestive of CD prior to diagnosis
- Children with CD had 1.4 x greater risk of **psychiatric disorder** than healthy controls (mood, anxiety, eating, and behavioural disorders, ADHD, autism spectrum disorders, intellectual disability). Non-affected siblings of CD patients were at no greater risk
- Adolescents with good GFD adherence displayed more **adaptive coping**: used more planning, flexibility, and acceptance
- Adolescents with poor adherence were more likely to get frustrated at CD and refuse to accept the medical need for a GFD
- **Caregivers** (parents, spouses) of patients with CD were at heightened risk of depression and anxiety

Butwicka et al. (2017). Celiac disease Is associated with childhood psychiatric disorders: A population-based study

Ludvigsson et al. (2017). Anxiety and depression in caregivers of individuals with celiac disease: A population-based study.

Olsson et al. (2008). The everyday life of adolescent coeliacs: Issues of importance for compliance with the gluten-free diet.

Questions?



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