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NHS South London and Maudsley NHS Foundation Trust

Working with young people with eating disorders:

considerations for busy practitioners

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IASW CAMHS Special Interest Group Conference
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Plan for this morning

- Introduction and personal work context
- Diagnosis and presentation of eating disorders
- Assessment and treatment reflections
- Overview of the '5-step model'
- Considering stigma and its effects

Please feel free to ask questions as we go

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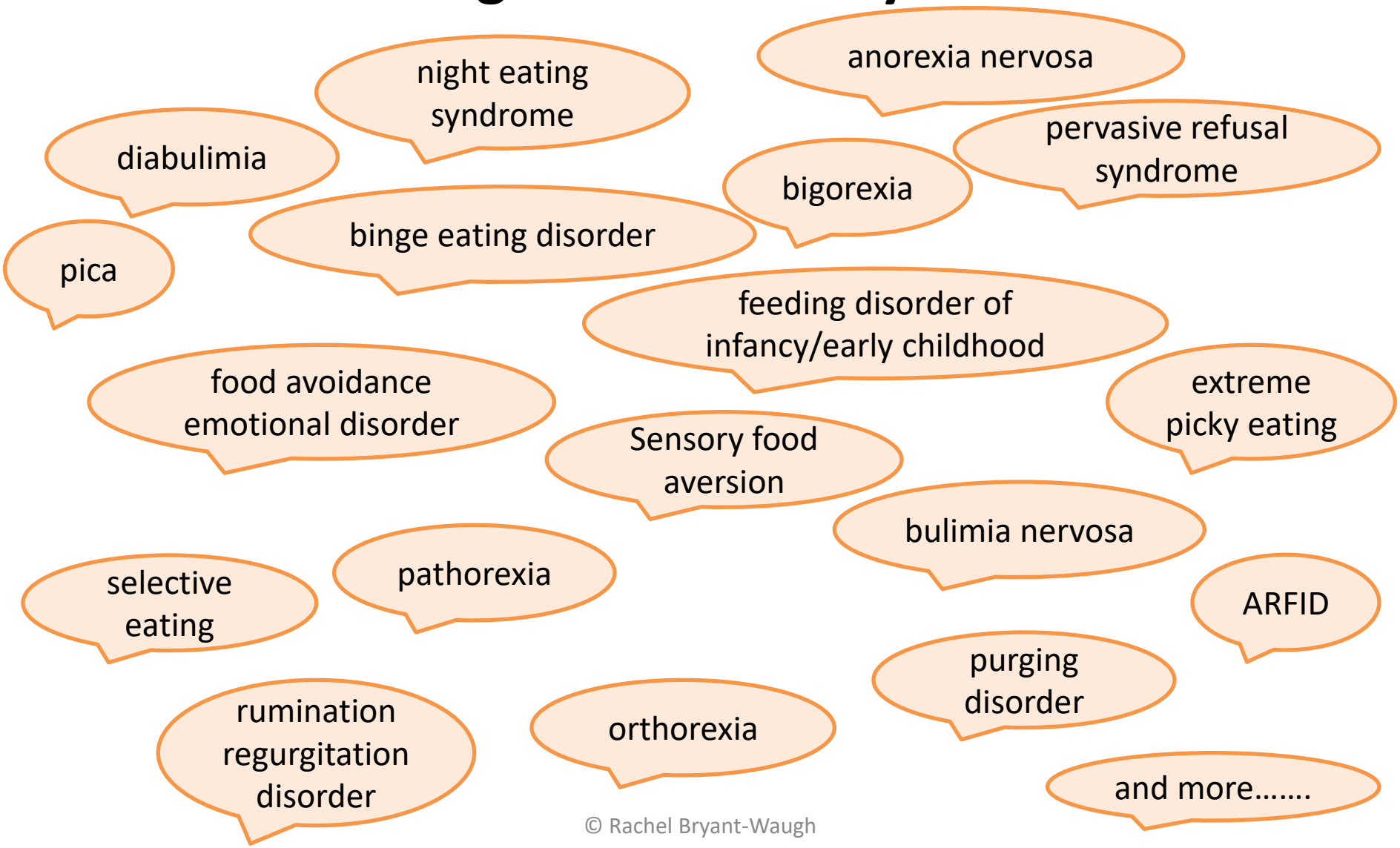
What eating disorders are you aware of?

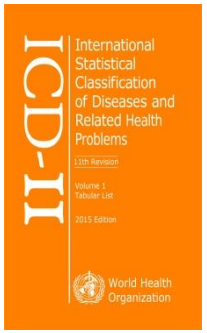


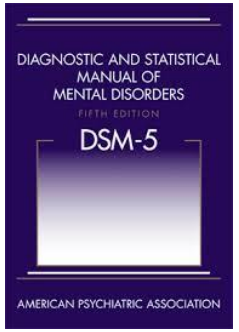
Feeding and Eating Disorders in 2019

- Pica
- **Rumination disorder** or **Rumination/regurgitation disorder**
- Avoidant/restrictive food intake disorder (ARFID)
- Anorexia Nervosa
- Bulimia Nervosa
- Binge Eating Disorder

Atypical anorexia nervosa
Subthreshold bulimia nervosa
Subthreshold binge eating disorder
Purging disorder
Night eating syndrome

- **Other specified feeding and eating disorders (OSFED)**
- **Other feeding or eating disorders**
- **Feeding or eating disorder, unspecified**





Pica

- Persistent eating of non-food substances - examples include chalk, soil, talcum powder, plaster, paper, cloth, hair, pebbles - can be dangerous and cause poisoning or obstructions

- Can be secretive and concerning to the individual

- Sometimes occurs in the context of anorexia nervosa (e.g. tissues) to allay hunger

- Often occurs in the context of LD/autism - may be a strong sensory / stimulus seeking or self-soothing component

Rumination disorder ("chew and spit disorder")

- Swallowed food is regurgitated and re-chewed then re-swallowed or spat out- regurgitation appears effortless and can be easily missed
- May be associated with low weight and can have serious medical consequences (e.g. aspiration, malnutrition; oesphageal damage)
- May be experienced as pleasurable, particularly after eating certain foods
- Often has a self-calming emotion regulation function and often seen in context of LD/developmental disorders

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ARFID

- Avoidant/restrictive food intake disorder - has extended and replaced ‘feeding disorder of infancy and early childhood’

- Eating or feeding disturbance with failure to meet nutritional and/or energy needs and one or more of the following:
  - significant weight loss (or failure to gain weight or faltering growth in children)
  - significant nutritional deficiency
  - dependence on enteral feeding or oral nutritional supplements
  - marked interference with psychosocial functioning

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ARFID in ICD-11

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Avoidance or restriction of food intake that results **in either or both** of the following:

- The intake of an **insufficient quantity or variety of food** to meet adequate energy or nutritional requirements that has resulted in significant weight loss, clinically significant nutritional deficiencies, dependence on oral nutritional supplements or tube feeding, or has otherwise **negatively affected the physical health** of the individual

- **Significant impairment in** personal, family, social, educational, occupational or other **important areas of functioning** (e.g., due to avoidance or distress related to participating in social experiences involving eating)

Claudino et al. BMC Medicine (2019) 17:93

ARFID in ICD-11

- The pattern of eating behaviour is not motivated by preoccupation with body weight or shape or by significant body image distortion

- Restricted food intake and consequent weight loss (or failure to gain weight) or other impact on physical health is not due to unavailability of food, not a manifestation of another medical condition (e.g., food allergies, hyperthyroidism), and not due to the effect of a substance or medication (e.g., amphetamine), including withdrawal, and not due to another mental disorder

Claudino et al. BMC Medicine (2019) 17:93

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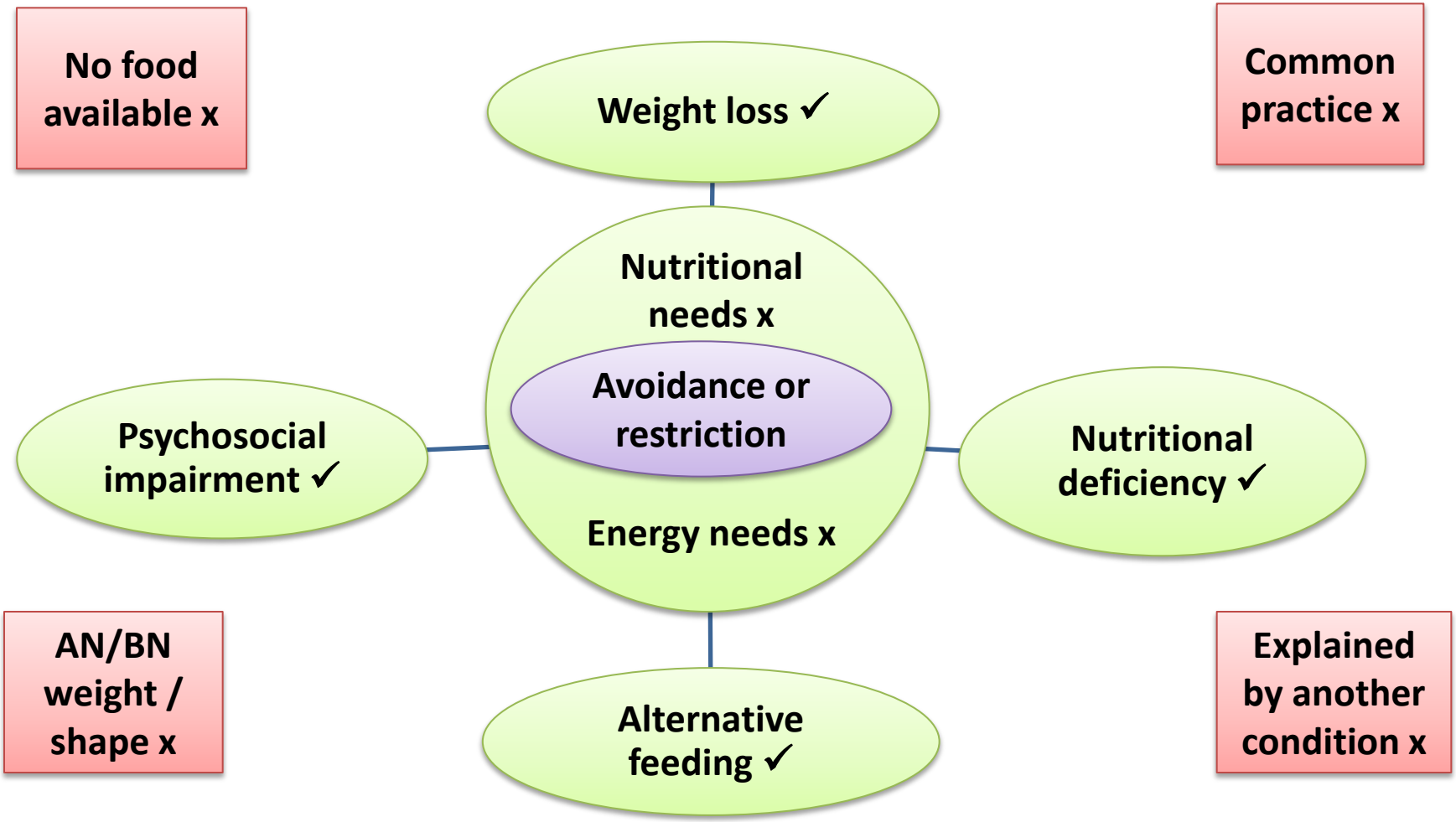
ARFID diagnostic requirements



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Individuals with ARFID may be:

- Under, normal or overweight (in children growth may be adversely affected) and of any age
- Nutritionally compromised
- Tube dependent/dependent on oral supplements
- Experiencing significant interference with social and emotional development and functioning, to include effects on the family and personal relationships

Important to remember

- ARFID is just a new term – **it is not a 'new disorder'**
- In is one of the 'feeding and eating disorders' – as are AN, BN, BED, pica and rumination disorder
- The difficulties ARFID covers used to be called by a variety of other names, to include:

Food avoidance emotional disorder
Food phobia
Sensory food aversions

Choking phobia
Food refusal
Infantile anorexia

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Anorexia nervosa

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- Restriction of energy intake relative to the individual's requirements leading to **significantly low body weight** in the context of age, sex, developmental trajectory, and physical health

- **Intense fear** of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain

- Disturbance in the way in which one's body **weight or shape is experienced**, undue influence of body shape or weight on self-evaluation, or persistent lack of recognition of the seriousness of low body weight

Restricting sub-type

Binge eating/purging subtype

'Girl, 15, who went on a post-Christmas diet dies from anorexia in a year'

Daily Mail Sept 2010

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Bulimia nervosa

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- The person engages in recurrent episodes of **binge eating** – this involves a large amount of food accompanied by a sense of lack of control

- The person engages in recurrent '**compensatory behaviours**' intended to prevent weight gain (e.g. vomiting; laxative or other medication misuse; fasting; or excessive exercise)

- The binge eating and inappropriate behaviors both occur **at least once a week** for 3 months (but is often more)

- **Self evaluation** is unduly influenced by body shape and weight

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Binge eating disorder (BED)

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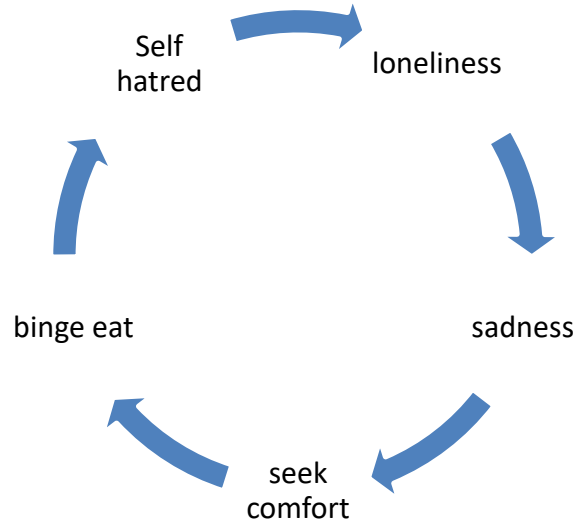
- As in bulimia nervosa, there is recurrent **binge eating** but this is **NOT associated with compensatory behaviours**

- Binge eating is associated with eating more rapidly than normal, eating until uncomfortable; eating when not hungry; eating alone because embarrassed; feeling disgusted with oneself, depressed, or very guilty afterward

- There is marked distress regarding binge eating

- People with BED tend to be overweight



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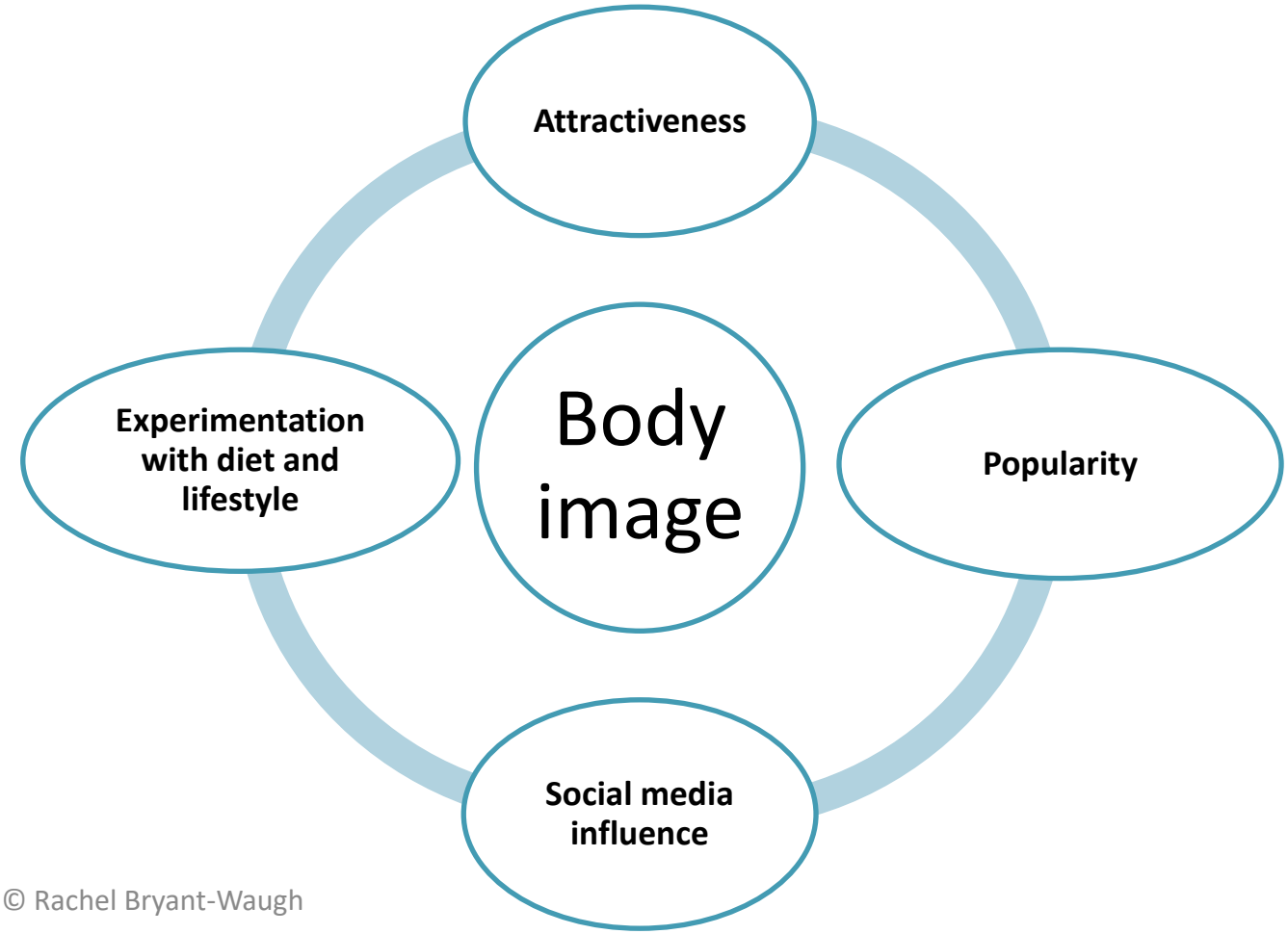
Body image in adolescents

- Up to 50% of 11-13 year old girls wish they were thinner



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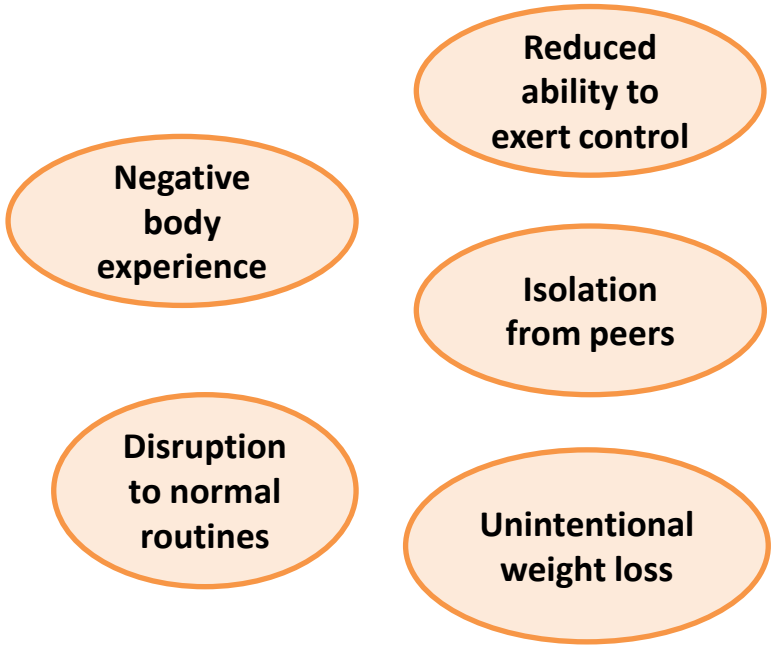
What increases vulnerability?

- Weight teasing
- Bullying/cyberbullying
- Social media exposure
- Family and peer dieting
- Certain personality style
- Poor self esteem
- Sense of not fitting in
- Experiences of failure
- Pubertal development
- Membership of specific groups (e.g. gymnastics, ballet)
- Physical conditions/illness

- Combinations of the above



When should I get worried?

- Constant comparisons with others and negative statements about appearance
- Significant drop in self confidence / reluctance to socialise / increase in perfectionistic tendencies
- Increase in length of time spent in bathroom
- Withdrawal from family mealtimes
- Extreme dieting and/or exercising
- **..when body image begins to impact negatively on behaviour and mood**

Negative body image is **part** of an eating disorder but **not the primary cause** of an eating disorder

Weight and shape begin to take over as the **primary means of judging self-worth**

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Body image: to sum up….

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- Negative statements and body feelings are **very common** in adolescence - most develop a manageable body image by late teens/early adulthood

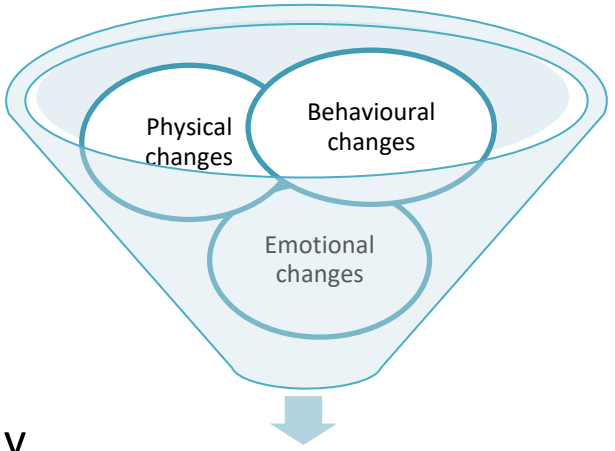
- Certain situations may heighten awareness and dissatisfaction

- There are lots of good resources on YouTube, websites, etc. - if you think a young person is really struggling – talk with them!

Help to build resilience….

What is the best way to identify early?

- For AN and BN don't just focus on weight
- Early signs are much more likely to be related to changes in behaviour and mood
- Young people with medical conditions in may be particularly preoccupied with their bodies and particularly vulnerable to feeling dissatisfied and isolated
- Given the difficulty of treating AN in particular early identification is very important….
- …remain alert and take an interest in the individual



Warning signs

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How should we assess ED's?

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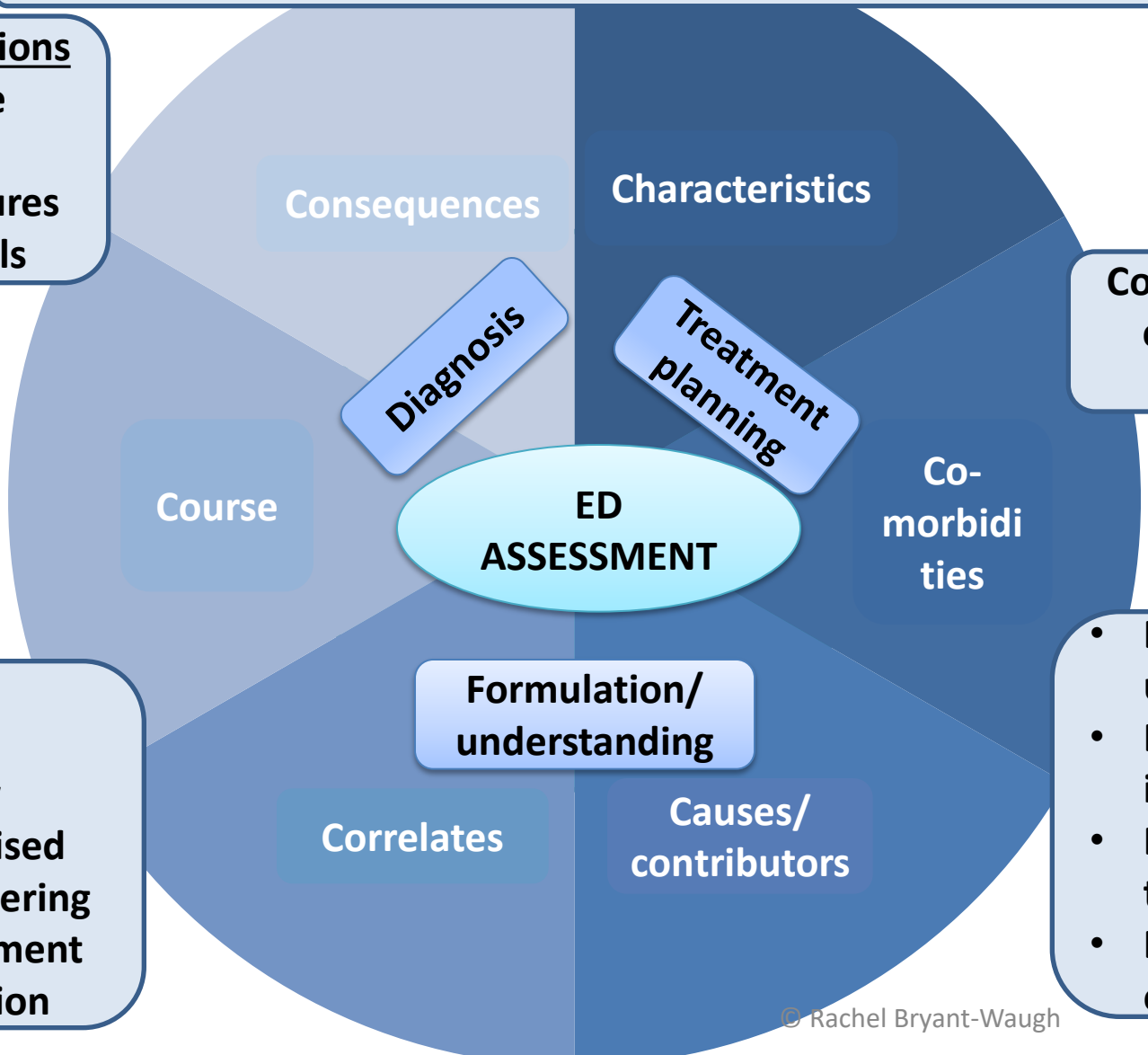
What information is needed and how is this best obtained and used?

Considerations
- Purpose
- People
- Procedures
- Protocols

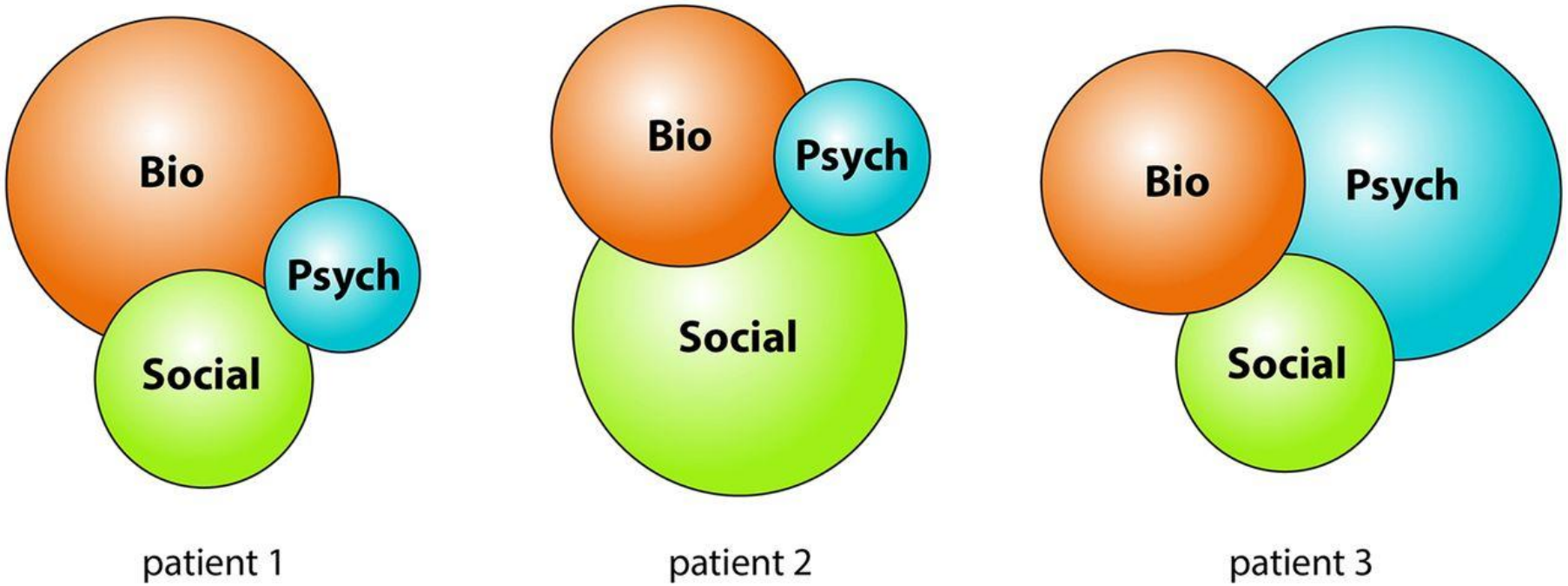


Combined audit/ collaborative research

Methods
- Clinical interview
- Standardised data gathering
- Measurement
- Observation

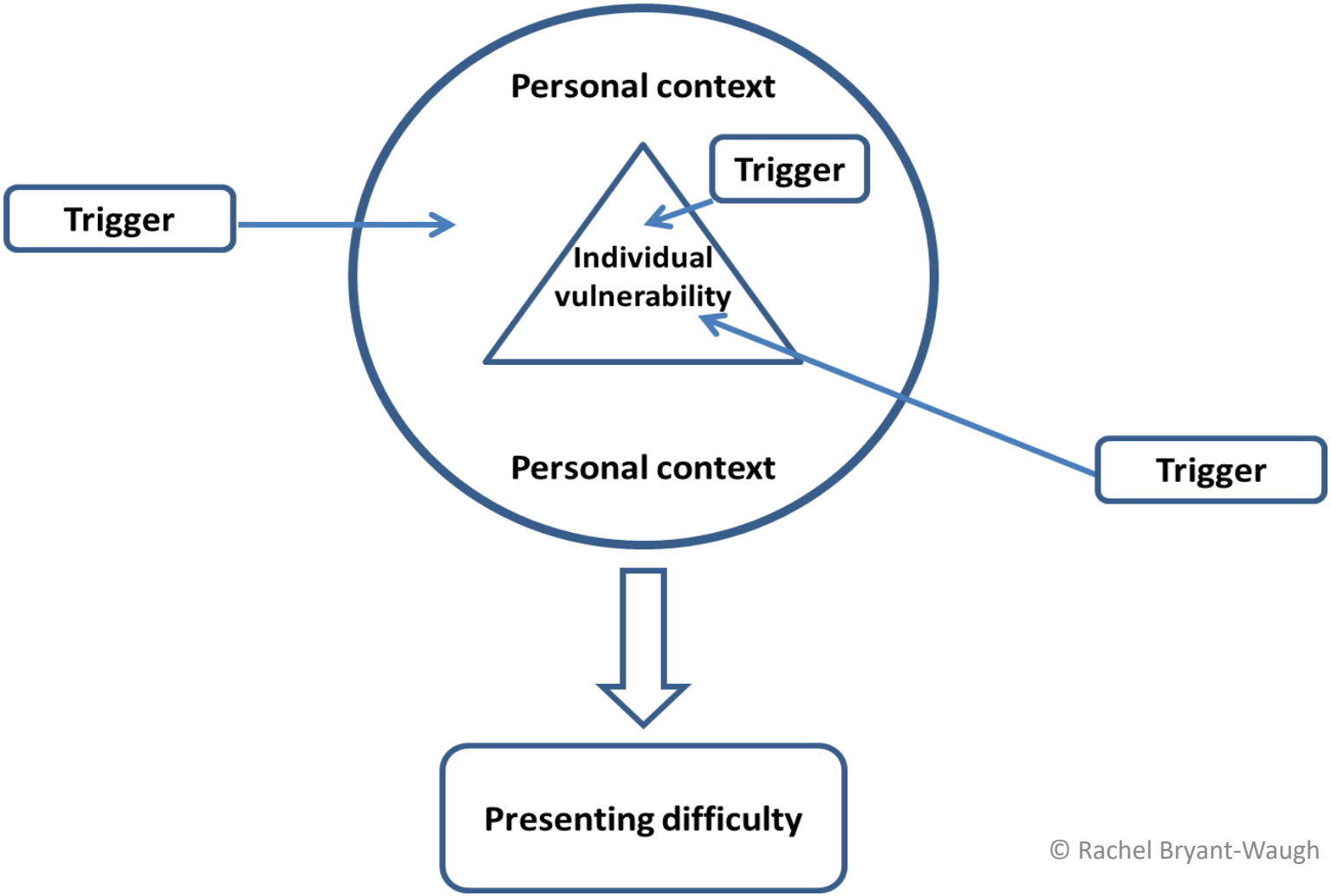
- Better understanding
- Better identification
- Better treatment
- Better outcomes

Assessment requires biopsychosocial approach



with multi-disciplinary involvement

Model for understanding the development of difficulties



EBP is the **integration** of clinical expertise, patient values, and best research evidence into the decision making process for patient care

Best research evidence - usually found in clinically relevant research, conducted using sound methodology

Clinical expertise - the clinician's cumulated experience, education and clinical skills

The patient brings to the encounter **his or her own personal preferences** unique concerns, expectations, and values

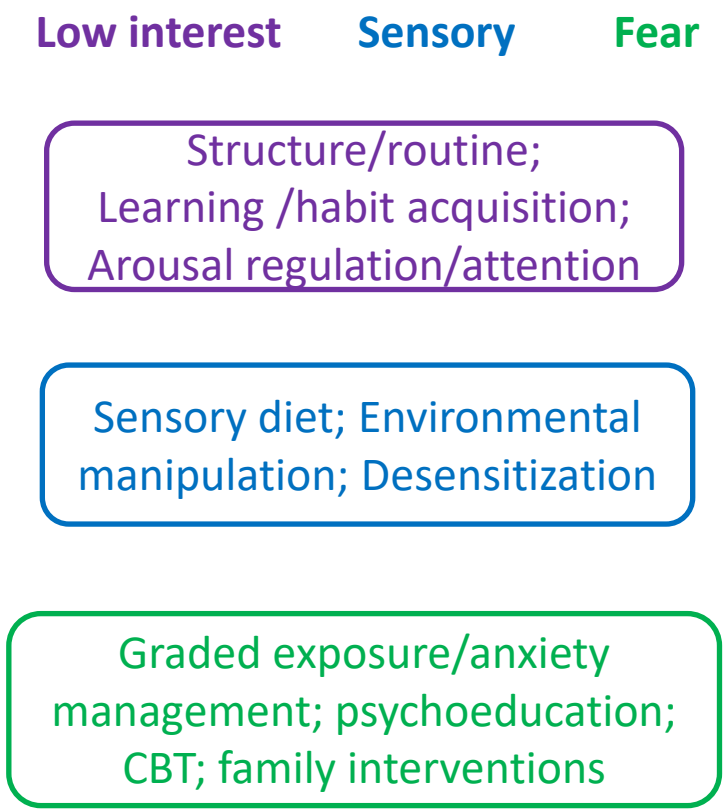
(Sackett D, 2002)

Evidence based guidance for eating disorders

- Family interventions (FT-AN or FT-BN) - To address the eating disorder; To support all family members
- Individual interventions (CBT-ED or Adolescent focused psychotherapy) - With some family input
- Medical interventions – stabilization, management and monitoring
- **No evidence** for medication as sole or main treatment for AN, BN or BED
- For BED – CBT approaches adapted with family input

What about ARFID, pica and rumination?

- ARFID includes individuals who restrict food or have limited intake on basis of:
  - lack of interest (appetite), distractibility, overarousal
  - food texture, appearance, temperature, brand
  - specific concern related to food intake or previous aversive experience, e.g. choking, vomiting



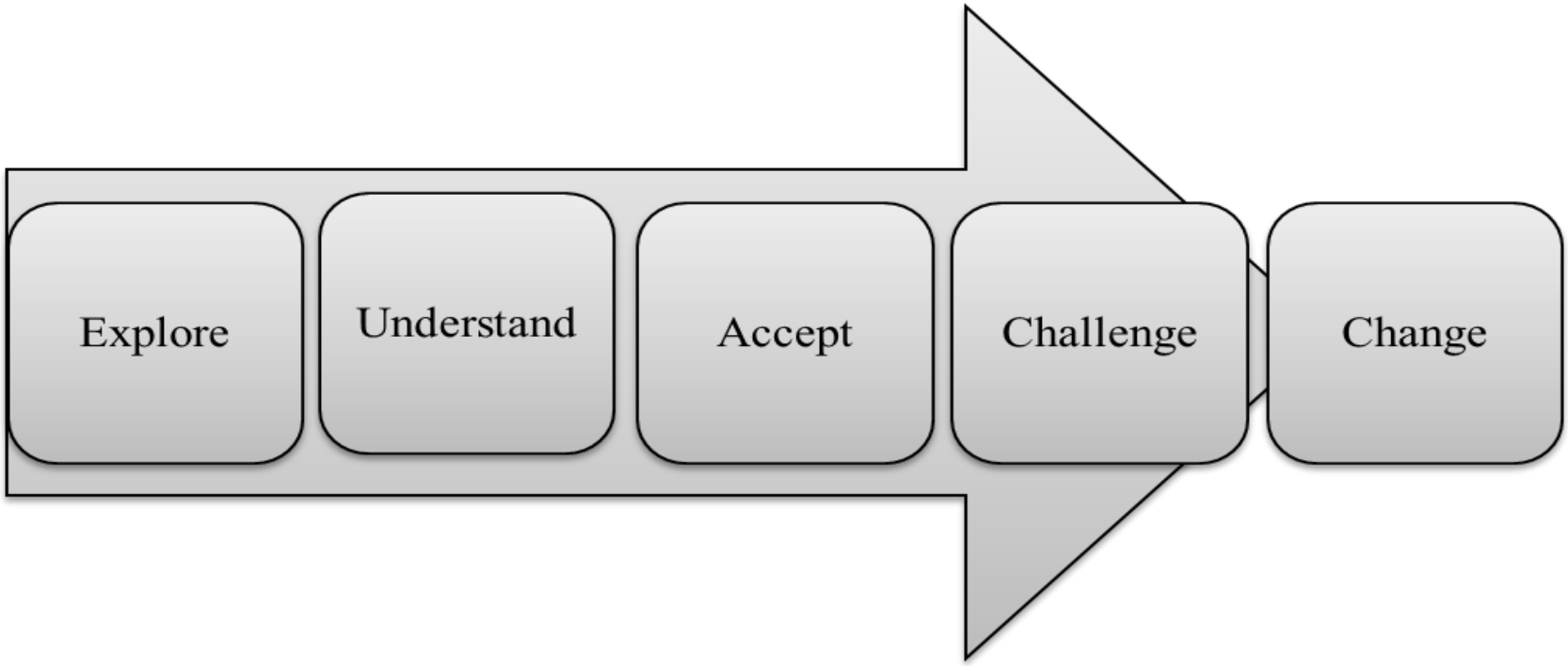
What about ARFID, pica and rumination?

- In pica and rumination disorder exploration of the drivers and function of the behaviour is important

- Possible interventions include:
  - Habit reversal training
  - CBT approaches
  - Anxiety management
  - Family interventions
  - Environmental management
  - Medical management and monitoring

1. Enhance awareness
2. Competing response
3. Social support

The 5-step model towards change



Individual work

- Often extremely important
- Evidence base for individual work is relatively weak in terms of specific approach
- Often hard to know how best to proceed….
- ….led to development of ‘5 step model’

Background to development of the 5 step model

- Way of working developed in the context of a pressurised clinical service for young people and adults with eating disorders
- Requirement to limit interventions in terms of sessions offered
- Need to develop some consistency in interventions offered by a team with very varied backgrounds

Background to development of 5 step model

- "Problem" is one that is in general very hard to give up
- Many people are ambivalent about treatment
- Eating disorders are 'functional disorders' – they serve a purpose

Background to development of the 5 step model

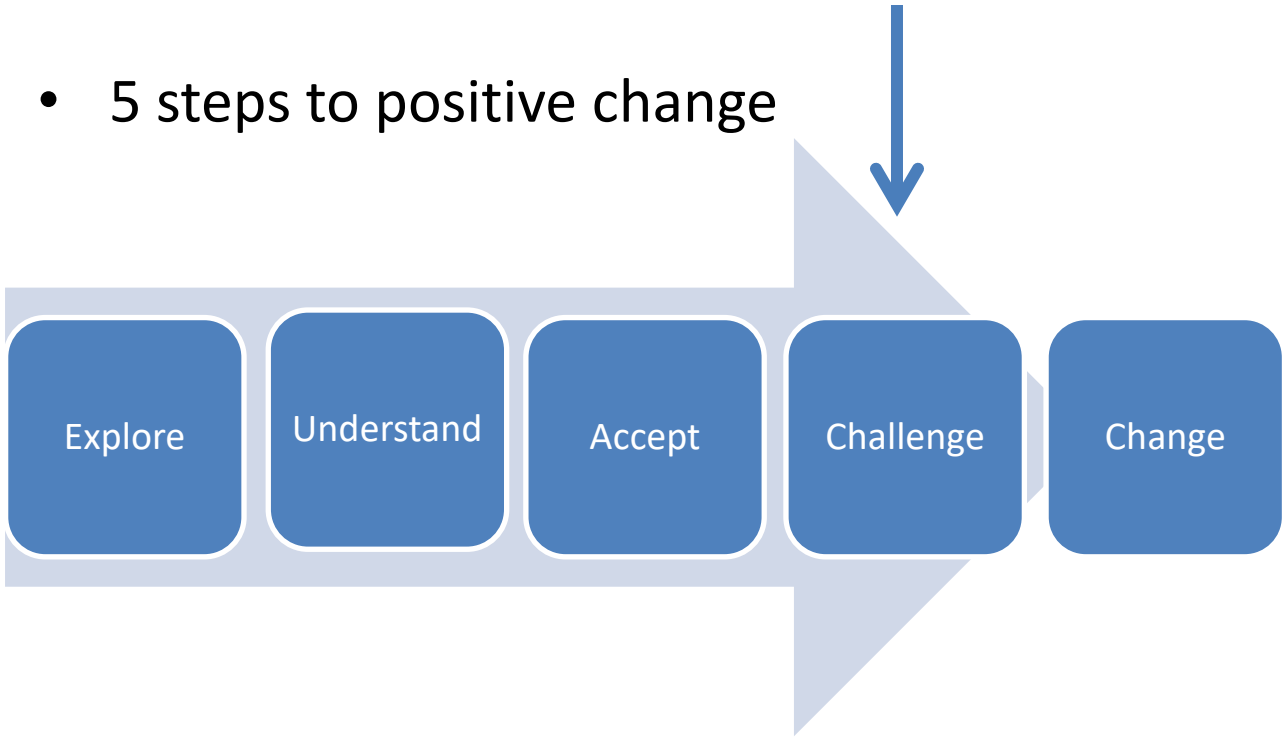
- An area where many clinicians feel uncertain how best to proceed
- All services tend to have staff who may not be very experienced in treating eating disorders
- Clinical presentations can create significant professional anxiety and frustration

Developmental – systemic approach

- A structured treatment approach intended to be used on an individual basis – developed with out-patients
- Based on existing, well described theories and broad therapeutic concepts
- Characterised by a collaborative, problem solving style

Importance of improving understanding

- Improving understanding essential to facilitating change
- 5 steps to positive change



Bryant-Waugh, R. (2006)
Pathways to recovery: Promoting change within a developmental systemic framework.
Clinical Child Psychology and Psychiatry 11: 213-224

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Five steps to achieve change

Person presents with problem

1.Explore

2. Understand

3. Accept

4. Challenge

5. Change

Achievement of + change

Step 1: Explore

- Personal history
- Family context and wider context
- Individual's support network
- Nature and timing of onset of problems and current status
- Over 2+ sessions – genogram and timelines

Step 2: Understand

- Main task here is to arrive at agreed formulation of why feelings, thoughts, behaviours have developed – why things are as they are
- Linking current responses with past patterns and personal context
- Joint identification of factors that may have played role in the development and maintenance of the ED

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Step 3: Accept

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- Make sure have a shared understanding focusing on function of thoughts, feelings, behaviours- all related to history and context
- Problem understood and accepted as person's logical response to aspects of her/his life
- Allows sense to be made of confusing/ conflicting thoughts, attitudes, behaviours – enhances sense of personal effectiveness + opens way for change
- Main tool – formulation letter

Step 3: Accept

- The formulation letter is given/sent to the person
- Offer opportunity to discuss and revise the letter until you have arrived at a shared understanding
- Then focus on ACCEPTANCE – the way things are now makes sense given what we know. It is neither good nor bad, it is just how things are, and we can understand it placed in its developmental systemic context

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Step 4: Challenge

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- How could things be different and what are the effects of making changes?
- What are the priorities for change and can we agree on those?
- This step is about challenging status quo, narrowing focus for change, and considering impact
- Tools – worksheets

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Step 5: Change

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- Desired changes identified in 3 areas - weight and eating; meaning of weight and shape; communication – plus others as appropriate

- Goals collaboratively formulated – clear, achievable and measurable

- Session content – agreeing active tasks; monitoring, reviewing, troubleshooting and revising goals as necessary

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Five steps to achieve change

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Explore

Understand

Accept

Challenge

Change

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Tool kit

- Genogram
- Time lines
- Formulation letter
- Worksheets
  - Function of my ED
  - Cost –benefit analysis
  - My fears and worries about change
  - Readiness to change
  - Treatment goals

Family tree

- Start with genogram – explain why
- Joint task, allows you to position yourself alongside person
- Can facilitate engagement through possibility of moderating eye contact, which can be experienced as threatening when combined with questioning on first meeting

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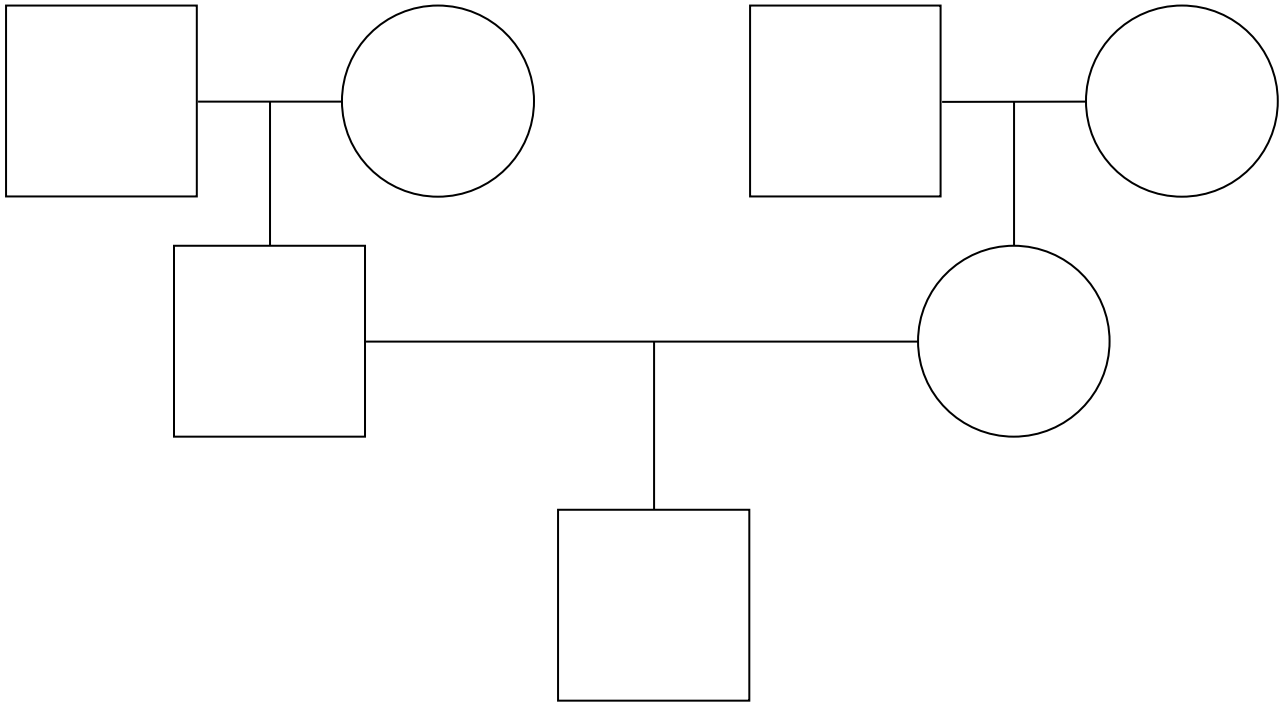
Genogram - male



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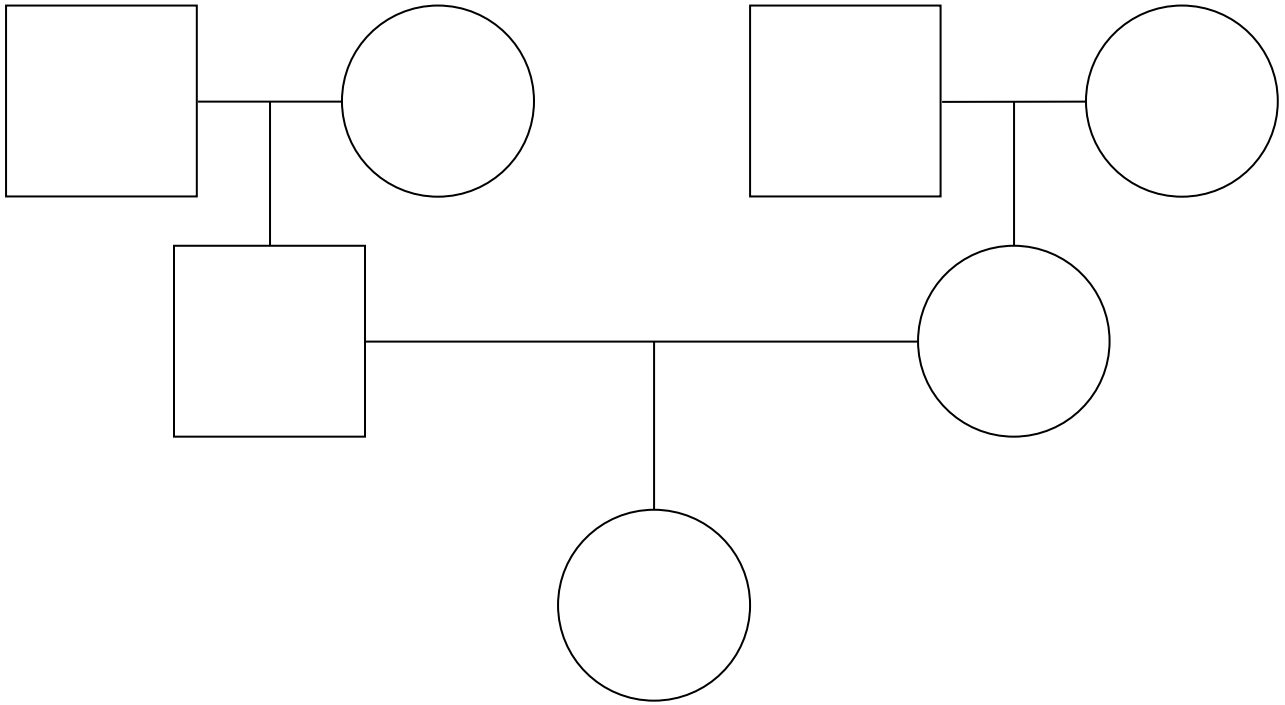
Genogram - female



Filling the gaps

- Encourage to take home (introduction of pattern of tasks between sessions)
- Keep copy to reflect on (reinforcement of joint nature of work)
- When complete move on to time lines

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Using the genogram

- Relationships – who gets on?
- Support – who can you talk to?
- Geography and occupation– who is available?
- Similarities – who is like whom?
- Family history of weight issues and dieting
- Family history of illness, disability, mental health problems

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Time lines

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Key life events

Weight and shape concerns

Eating difficulties

Weight changes

Age along bottom axis, entries written from line up vertically

Using the time lines

- Start with life events – space out from birth to current age

- Go with individual – some prefer to start at one end and work to the other, others find it easier if you prompt by putting in key transitions – e.g. birth of siblings, school, further study, work, moves, relationships, etc

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Eating, weight, shape timeline

- Often some cross over in account of life events
- Plot start of periods, etc on this one
- Often individuals make their own links and realisations – essential to have both lines of one sheet

Time lines

- Again copy can be taken home to be worked on, with copy kept
- Some people become very distressed – fine to leave sections "to come back to". Important thing is to clearly identify a difficult period.
- Where possible make reference to what you know from the genogram throughout – linking and making sense of things are key concepts

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On to next step…..

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- Having done genogram and timelines (Step 1 = Explore), now ready to move to next step (Step 2 = Understand)
- This is achieved by you putting together the information you have obtained in the form of a “formulation letter”
- This letter has a standard format and represents an attempt to make sense of the person’s current presentation

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Format of formulation letter

- Introduction to way of working
- 1-2 paragraphs on genogram
- 1-2 paragraphs on timelines
- Emphasis on current behaviour, thoughts and feelings being understandable and functional
- Opening up the way for possible change

Step 3: Accept

- The formulation letter is given/sent to the person
- Offer opportunity to discuss and revise the letter until you have arrived at a shared understanding
- Then focus on ACCEPTANCE – the way things are now makes sense given what we know. It is neither good nor bad, it is just how things are, and we can understand it placed in its developmental systemic context

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Moving on: challenge + change

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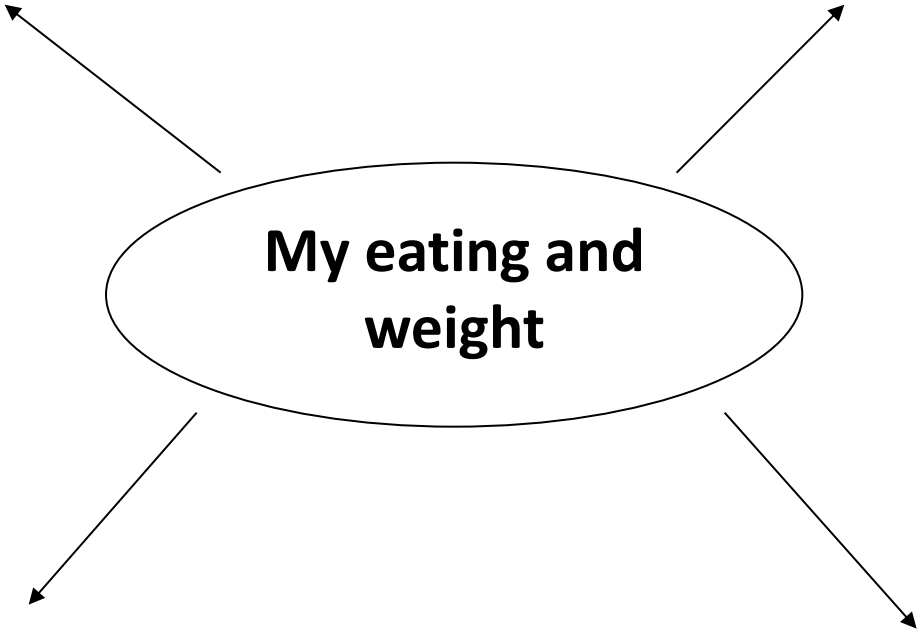
Use of work sheets:

1. The function of my eating disorder
2. Cost benefit analysis
3. Fears and worries about change
4. Readiness to change
5. Goal sheets

What does my eating disorder do for me ?



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Cost- benefit analysis sheet

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It is not uncommon for people to feel uncertain about giving up their eating disorder. List below the 'pros and cons' of changing your eating.

Positives of moving on

Negatives of moving on

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Readiness to change sheet

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Rate the following to help you think about how ready you are to change

Overall, I feel the benefits of change out weigh the negatives

1----------2----------3----------4----------5

I do not agree with this at all	I agree with this a moderate amount	I totally agree with this

Rate how often you feel ready to begin to let go of your eating disorder

1----------2----------3----------4----------5

never	sometimes	always

Rate, on average, the extent to which you feel your eating disorder is part of who you are as a person

1----------2----------3----------4----------5

not at all part of me	part of me a little bit	a significant part of me

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Treatment goals

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Please think of things you would like to achieve in relation to the three areas below. If you can't think of anything to write for any of the areas, don't worry, just leave it blank

- **Behaviours to do with managing food, eating and weight:**

- **The importance weight and shape has in my life:**

- **How I communicate my needs, feelings and wishes to others:**

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Treatment goals

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Please list below the areas you wish to work on during treatment, and also think about what you are going to do in order to make each happen

Behaviours to do with managing food, eating and weight:

Goal Plan

The importance weight and shape has in my life:

Goal Plan

How I communicate my needs, feelings and wishes to others:

Goal Plan

•

Key features of 5 step model

- Early, important task is to explore personal history, to identify past patterns of response to developmental change and pressure and consider their ongoing influence

- Another early task is to explore family history and function from individual's perspective and seek to understand development and maintenance of problem within family and social context

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Key features of 5 step model

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- Development of collaborative, supportive relationship as vehicle for change.
- Power differential minimised and work considered a joint venture.
- Willingness and confidence to accept personal responsibility fostered.
- Enhancement of autonomy and self worth.