

# Empowering Parents To Still be Parents in the Fight Against Anorexia Nervosa:

## Models of Family Involvement with Young Adults 18-25 years old

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### ABSTRACT

Kids do not magically stop being their parents' kids when they turn 18 years old. Nor does that birthday change the fact that eating disorders are biologically based illnesses severely impairing one's ability to feed themselves due to the impact of malnourishment on the brain. Parents shouldn't be expected to not worry, not get involved and not try to secure effective treatment for their sick child with a life-threatening illness because that child is now considered by law, an adult. Family-Based Treatment (FBT; Lock et al., 2001) has been shown to be effective in the treatment of adolescents with Anorexia Nervosa through the age of 18 years old (Lock et al., 2010). With the third stage of adolescence going into the early to mid 20's and the scientific data further supporting this relative to brain development (CITE), we are left to wonder what about this cohort of adolescents? The FBT outcome data, combined with the difference in the drop-out rates between FBT and individual therapy with adults (Lock et al., 2005), relapse rates amongst adults in individual therapy, (Halmi et al., 2005), the psychiatric and medical complications of the illness, and continued financial support and involvement these families led us to question how we could extend the success of FBT and family involvement of those in our Adolescent Program (18 years old and under) with those in our Adult Program falling between 18-25 years old? Although not dismissive of the differences between them, weren't these two groups more similar than they were alike? We propose several models of parent involvement, including but not limited to FBT-Y, in the treatment of those aged 18-25 with anorexia nervosa.

### INTRODUCTION

When providing empirically based treatment for adolescents between 13-18 years old, parents are put in a position to do something that is core to parenting-nourishing and caring for their children. With expertise and guidance of a FBT-trained multidisciplinary team, parents are put at the frontlines in a battle for their child's life with a high likelihood of a positive outcome. In a traditional treatment model, the parents of young adults are not given this same opportunity although the illness is just as life-threatening. Given what we know about what does and doesn't work in treatment led us to ask ourselves the following questions:

- Was not actively involving parents of those 18-25 years old more directly, let alone requiring it, making treatment less effective given the plethora of research about barriers to treatment for adults with AN?
- Was not taking the time to educate, empower, and involve these parents as part of the team (vrs. adjunct to the team) decreasing the chances of a good prognosis?
- Would increasing their involvement increase the likelihood of reversing some of the medical and psychiatric complications that can become irreversible based on age and timing of refeeding?
- Was trying to negotiate with a 18 year old to eat and to gain weight going to be effective when we simultaneously were running an adolescent FBT program that taught parents about how ineffective this when the brain is malnourished?
- Did we find ourselves doing trying anyway because on some level we fear being "adults" gives them "right" to make decisions for themselves, ones which could kill them?
- Is it appropriate to not give these loving and petrified parents the psychoeducation that relieves them of their unfounded guilt and despair, having believed that they must have done something wrong when AN is a biologically based illness no more caused by parents than juvenile diabetes?
- Does it make sense to close the door on the committed and loving parents whose involvement may improve the course of treatment and prognosis?
- Don't all higher levels of care for adults with AN all involve someone feeding the individual as part of treatment given food as the critical intervention for stabilization and the likelihood of other forms of therapy being effective?
- Shouldn't we reinforce to parents that yes, they SHOULD be worried when they are informed their college age daughter passed out on the steps in the dorm and has a low heart rate even though the health center wasn't concerned?
- Shouldn't we reassure parents that OF COURSE they are presenting like an anxious, highly because she has an incredibly sick child instead of judging them?

### WHEN A CHILD TURNS 18 YEARS OLD, ARE PARENTS SUPPOSED TO STAND BACK AND WATCH THIS ILLNESS POTENTIALLY KILL THEIR CHILD BECAUSE SHE/HE IS NOW AN "ADULT?"

Through a multidisciplinary approach that involves similarities and differences from the traditional FBT model, this poster highlights two different models for actively involving the parents of young adults in treatment as well as a specific type of parent coaching that simultaneously supports treatment goals and adolescent developmental issues when appropriate.

### MODELS OF FAMILY INVOLVEMENT

#### I. FBT-Y

- Parents' role similar to that described in FBT manual.
  - Play direct role with the food and management of behaviors (ie protocols around bathroom use after mealtimes, etc.).
  - Deviates from manual by often involving nutritionist and meal plan/meal cards which parent implements with individual variations on degree of specific information about food.
  - May involve collaboration in Phase 1 if supports treatment goals.
- Rationale for adaptations:**
- Parents may be more reluctant to reintroduce higher density and/or fear foods given age than parents of younger adolescents.
  - Families may not complete all the three phases of FBT and experience more ambivalence about their direct involvement with the food with the remission of acute psychiatric or medical symptomatology.
  - Patients may re-engage in developmental tasks sooner than those in early/middle adolescents (i.e. returning to college once Phase 1 goals met) and require more structure for managing food due to absence of Phase 2 interventions.
  - Participation of Adult Day Treatment Program requires meal plan.
  - Young adults who experience a co-morbid mood disorder may be unable to make appropriate choices as a result once weight restored yet eat appropriately if decision-making is minimal.

#### II. Parental Involvement

This model involves a range of interventions that may or may not involve involvement with food/monitoring of behaviors and can include some or all components of this model. The specifics are often determined by the clinical team after the assessment and adapted relative to the phase of treatment. Variables considered for these decisions often include:

- Medical stability
- Length of illness
- Presence of co-morbidities
- Patient's motivation/insight about treatment goals
- Family's willingness/ability to engage in treatment process
- Previous treatment failure
- Living arrangement of patient and parents
- Ability to manage meal planning/intake needs relative to Adult Day Treatment expectations and goals

**Interventions:**

- Coaching parents and patients on emotion regulation and interpersonal effectiveness skills around illness/treatment and adolescent developmental issues.
- Identifying ways that parents can increase accountability/compliance outside of treatment hours.
- Involving parents in medical appointments due to brain malnourishment and inability to grasp acute and chronic medical consequences of their illnesses.
- Meetings with therapist on team without patient for psychoeducation, support and skills coaching relative to the illness.
- Providing emotional support/accountability/distraction/assistance with food secondary to patient's treatment goals of identifying such needs and using skills to manage them to prevent behaviors.

**Rationale for adaptations:**

- Family involvement adjunct, but not primary intervention, as patient able to utilize treatment interventions in Adult Treatment Programming effectively and meet treatment goals without FBT-Y.
- High expressed emotion within family may not be effective for direct involvement with food/behavior until system has received adequate skills coaching to do so.
- Co-morbidities warrant additional interventions.

#### III. Parent Contracts

- Intervention based on reinforcement of parents' role in their child's safety and well-being given lethality of the illness, judgment/decision-making ability due to ED and adolescent brain development despite legally identified as an adult.
- Created by parents with psychoeducation/consultation from FBT therapist to identify criteria for young adult to re-engage in age-appropriate activities once stabilized (i.e. going away to college, driving car which is owned and insured by parents, etc.)
- Involves empowering parents to think about their needs/limits/parameters for their child and reinforcing their validity/appropriateness relative to impact of the illness
- Functions to assist patients in reinforcement of mindset that ED behaviors as "non-negotiable" that occurs throughout FBT.
- Provides dialectics for patients should urges increase and/or motivation begin to decrease if contract around ability to engage in developmental tasks (ie "I want to lose weight" and, at the same time, I want to stay at school" which may reinforce use of skills for compliance as both cannot co-exist given objective data monitored per contract).

### EXAMPLE OF PARENT CONTRACT CREATED BY PARENTS & FBT THERAPIST

**Contract utilized to support family in making decisions around sending young adult away for college:**

- X has demonstrated radical acceptance of not having ED behaviors possibility of continued cognitions and urges (which is measured/reinforced by items below).
- X must demonstrate ability to stay within weight range for minimum of 6 months prior to leaving for school.
- X must demonstrate ability to maintain minimum while taking primary responsibility for management of food given phase of treatment; includes demonstrating efforts to allocate enough time for breakfast at home before school and packing snacks/lunch.
- Should X need more support related to food and/or otherwise in a particular moment/in general, she/he will be communicate this with parents (with parents' agreement to see this as skillful vrs. indication of not being able to go to school unless patterns occur).
- If weight goes out of range, X will work with therapist to identify plan for prompt return to appropriate range and share plan with parents.
- X will continue to demonstrate responsibility/compliance with medication and treatment expectations.

**Contract put in place when agreed upon by family, team, patient for plan to start/return to college away from home w/ongoing stabilization of ED:**

- X agrees to sign relevant releases to allow parents access to young adult's medical information. All efforts will be taken to maintain X's confidentiality w/ therapist unless pertains to significant medical and/or psychiatric risk.
- Should this occur based on team's clinical judgment, X will be encouraged to share information with parents but if unable/unwilling, therapist will notify parents.
- X agrees to weekly weigh-ins and vitals check at student health center/with identified ED specialist if in area.
- If X fails to show up for this standing appointment, clinic will notify parents.
- If X's weight goes below identified appropriate range, X will have one week to work with on campus team to regain.
- If X unable to return weight to within range, parents will be notified of weight by student health clinic/therapist via email. If parents do not receive an email on a particular week the weight is assumed to be within range or is not of clinical concern given 1 wk. plan for X to reverse loss.
- If X is unable to regain and/or continues to lose, parents are informed that X has demonstrated two data points outside of range and further discussion required.
- Similar parameters apply for vitals; information will also be faxed from Student Health to current ED medical specialist who will determine if HR/orthostasis require more immediate medical intervention.
- Parents will schedule appointment at CCED FBT therapist with whom the contract was made to discuss concerns/plan (details may include increase in therapeutic support, nutrition consult, reduction of course hours, etc.)
- Should plan not result in stabilization of weight/vitals, schedule parent coaching re:interventions such as medical leave or withdrawing from school.

### CONCLUSIONS

Parents continue to be their child's parents when they turn 18 years old and anorexia nervosa continues to be a life-threatening illness with irreversible medical consequences, psychiatric impairments and a poor prognosis if not treated aggressively. Given what we know from the adolescent research with FBT, the impact of eating disorders on the brain and the fact that they love their children no differently than they had more legal rights to their care, parents should be empowered, educated and included in the treatment of their 18-25 year old children.

### REFERENCES

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