A F.E.A.S.T. FAMILY GUIDE TO

EATING DISORDER TREATMENT

HOW TO CHOOSE A TREATMENT TEAM FOR A LOVED ONE WITH AN EATING DISORDER IN THE U.S.

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PORT IN A STORM:

HOW TO CHOOSE A TREATMENT TEAM FOR A LOVED ONE WITH AN EATING DISORDER IN THE U.S.

OUR LOVED ONE HAS AN EATING DISORDER AND NEEDS TREATMENT. WHOM CAN WE TRUST?

Families do have choices when it comes to choosing an eating disorder treatment provider. Getting a list of specialists from your health insurance company or a local referral from your family doctor is just a starting point for one of the most urgent and important decisions you will ever make. While you may not be an expert in eating disorders, you are an expert when it comes to your child and you have valuable insights, intuitions and parenting skills that are critical to the recovery process. Your confidence and trust in yourself as a caregiver will go a long way towards reassuring your loved one that they do not have to face this disease alone.

Choosing treatment is a confusing and daunting task. You may consult a provider who recommends a certain approach, and then have another provider suggest an entirely different plan of action. You may be given glossy brochures that show beautiful facilities and smiling patients, and make all sorts of promises. It will be up to you, as parents, to choose an appropriate starting point for your child's treatment. The best way to make this decision is to educate yourselves by carefully researching your options, interviewing potential providers, and having specific goals in mind for your child's treatment. This guide is intended to help you with this process.

CAN EATING DISORDERS BE SUCCESSFULLY TREATED?

Yes. With appropriate expert and family assistance, there is always hope for successful recovery. Treating eating disorders is not easy, and the earlier the intervention, the higher the chance of success. Effective care usually requires a multi-disciplinary approach, specialized caregiving skills, and long-term vigilance. Although an eating disorder diagnosis may feel like a devastating blow to a patient and their family, it is an opportunity to begin a treatment process that can allow your loved one to restore their mental and physical health and live a full, successful life.

WHAT IS THE BEST TREATMENT APPROACH?

There are several different approaches to treating eating disorders. However, the immediate goals of ANY treatment approach should include:

- 1. Interruption of life-threatening behaviors
- Medical stabilization
- 3. Normalizing nutrition and/or weight stabilization
- 4. Development of a comprehensive, long-term treatment plan

Later goals should include:

- Identifying and treating psychiatric conditions that pre-date and/or parallel the development of the eating disorder, such as depression, obsessive compulsive disorders, or other anxiety disorders,
- 2. Understanding any biological and environmental vulnerabilities that maintain the eating disordered thoughts and behaviors,
- Working as a team, with families, to teach awareness of these vulnerabilities and integrate effective coping strategies into the patient's and family's daily life.
- Identifying and educating others in the community who will support the patient during later stages of treatment..

CAN I MAKE MY YOUNG ADULT CHILD GET TREATMENT?

Refusal of treatment, due to lack of insight about being ill, is a common symptom of an eating disorder. While many mentally ill patients who are a danger to themselves can be ordered into treatment programs, patients with eating disorders are too often permitted to act against medical advice and leave the urgent, often life-saving treatment they need and deserve. Just as for cancer or drug treatment protocols, treatment will not work if the medicine is watered down or treatment is interrupted or stopped.

The belief that a patient needs to retain their independence and choose to engage in treatment on their own is not supported by the evidence, and the consequences of ignoring or delaying medical and nutritional rehabilitation can be deadly. Many parents may have financial or other "leverage" they can use to encourage their young adult child to enter and remain in treatment. However, some parents may need to seek court-

ordered commitment to a treatment facility when their young adult child is unable to do so themselves. Many families find that cooperation will come more readily in later stages of treatment when the patient's thinking is not distorted due to unstable nourishment and other disordered eating behaviors that affect brain chemistry.

MY INSURANCE COMPANY GAVE ME A LIST OF PROVIDERS IN MY AREA. DO I REALLY HAVE MUCH CHOICE AS TO WHO WILL TREAT MY CHILD?

In private healthcare systems like the US, families are usually referred to an ED specialist by their Health Insurance Company or primary care provider. Most families with private insurance have a choice between innetwork and out-of-network care. Typically the choice of an out-of-network provider results in higher fees for the family and can be a limiting factor in finding affordable treatment. In addition, most private insurance policies, and Medicaid, place limits on the types and length of treatment services that they will pay for. Families should carefully research the details of their insurance coverage and make sure they understand what their options are for selecting and switching treatment providers.

Eating disorders are very difficult to treat and each patient's treatment needs will be different, but no less urgent. Sometimes the most appropriate and effective care for a patient will be found outside of the family's insurance network and geographic region.

While it is important to research the options available to you before choosing a treatment provider, it is even more important to periodically evaluate if that treatment is working and make changes if it is not. Parents have the right as caregivers to choose and change treatment providers and should not be afraid to assert those rights in order to ensure that progress is being made towards recovery. Skilled providers invite and respond to parental feedback about treatment progress. They revise the treatment plan based on this feedback.

While you may not be an expert in eating disorders, you are an expert when it comes to your child and you have valuable insights, intuitions and parenting skills that are critical to the recovery process.

FIRST STEPS:

HOW CAN WE RESEARCH OUR OPTIONS?

- Start by researching the types of treatment you are being offered and learn about the evidence-base for each option.
- Review the various published clinical guidelines and standards of care for treating eating disorders.
- Take the time to read about the current science on eating disorders and do not be afraid to go to sources written for professionals. Rely on information sources that are current, financially unbiased, and science literate.
- 4. Interview a range of prospective clinical teams and come prepared with specific questions. Take the time to fully understand the treatment team's approach, the day-to-day requirements of the program, and the role you as a caregiver will play in treatment.
- State your own concerns about the approach being described to you
 and make sure you feel listened to and included as a partner in your
 child's care. This is your right as a caregiver and your responsibility
 as a member of the treatment team.
- Read more about your rights as a caregiver under current public health policy and the "Worldwide Charter for Action on Eating Disorders" (www.aedweb.org/source/Charter/#.UsiUV_RDv74)
- Assess the family's resources as a household, what help you can expect from extended family and friends, and other resources available to you within the community.
- 8. Decide if your family can fully commit to supporting the treatment plan being presented to you.
- 9. Make a plan for beginning treatment, complete with time horizons for evaluating progress, and then make a back-up plan.

RELIABLE RESOURCES TO START WITH:

- Academy for Eating Disorders (www.aedweb.org)
- National Institute for Mental Health (www.nimh.nih.gov)
- F.E.A.S.T. (www.feast-ed.org)
- Maudsley Parents (www.maudsleyparents.org)
- National Eating Disorders Association (www.nationaleatingdisorders.org)
- F.E.A.S.T.'s Eating Disorder Glossary: (http://glossary.feast-ed.org)
- F.E.A.S.T.'s list of Clinical Guidelines: (www.feast-ed.org/resources.aspx)

Although the treatment plan for each patient will be unique, it is wise to start with the best-validated approaches and expert clinical advice.

WHAT DOES THE RESEARCH SHOW?

Many patients and their families credit long-term inpatient, residential or day treatment care as critical to recovery. However, there is little in the way of data to tell us how effective it actually is, or that one level of care works better than another. Recently, certain eating disorder (ED) treatments have been examined in well-designed studies. Some of the results have been surprising and call older, but still common, treatment practices and assumptions into question. Nevertheless, the map of treatment remains largely uncharted, and most treatments have not yet been tested. Although the treatment plan for each patient will be unique, it is wise to start with the best-validated approaches and expert clinical advice. Recent research has shown us some important facts about the treatment of eating disorders:

- Early intervention increases the chances for full recovery. Treatment for any ED should be considered urgent and not be postponed even if symptoms seem mild or do not meet all the established diagnostic criteria.
- Some of the 'evidence-base' in ED's has put older approaches in question. For example, the use of birth control pills for bone health in anorexia nervosa (AN) has not been supported. Causal theories about poor parenting and fear of oral impregnation have been discredited.
- For adolescents with AN, Family-Based Treatment (FBT) (also called the Maudsley Method), has the best results for the most patients. It is now considered the first recommendation for adolescent patients who are medically stable and fit for outpatient treatment.
- About 50% of adolescents with AN show recovery after a course of FBT, i.e., at or above 95% of expected body weight and demonstrating a substantial reduction or absence of eating disorder thoughts and behaviors.
- For adults with AN, there is no research support for one definitive treatment at present. However, several different psychotherapeutic

- approaches appear helpful, including Cognitive Behavior Therapy (CBT), interpersonal therapies, some psychodynamic psychotherapies, and even well-structured medical programs that include advice, education, support and encouragement. ¹
- For adults with Bulimia Nervosa (BN), the research support for CBT is strongest, and certain medications have been shown to be very helpful. There is also mounting evidence for the use of FBT and Dialectical Behavioral Therapy (DBT) with adolescents and young adults.

LEVELS OF CARE FOR EATING DISORDERS IN THE US

It is not unusual for patients to move from one type of care to another during the course of their treatment. Higher levels of care may alleviate distress, restore nutrition and stabilize symptoms in the short run, but best outcomes are likely when intensive outpatient treatment follows and continues after symptoms have abated and until recovery can be maintained by the individual. Patients need to know that therapeutic support should not stop because they have interrupted their symptoms. Below are descriptions of the most common types of treatment environments in the U.S. Please note that the terminology used in this guide may have a different meaning in other countries and/or health care systems.

Outpatient (OP): The patient lives at home and attends regularly scheduled (usually 45-50 minute) sessions at a therapist's office. This typically includes one or more sessions per week. The patient may be seen individually, with the family, in a group format with other patients, and/or sometimes in a multi-family group format. The type of therapy prescribed will depend on the age of the patient, the prescribed treatment plan, and the philosophy of the provider. Outpatient treatment does not usually include supervised meals.

Intensive Outpatient Program (IOP): The patient lives at home but spends some of their time at a clinic for therapy sessions and limited meal support. A common IOP schedule would be three hours per day, three days per week, and includes dinner.

www.feast-ed.org

¹ Focal psychodynamic therapy, cognitive behaviour therapy, and optimised treatment as usual in outpatients with anorexia nervosa (ANTOP study): randomised controlled trial. Stephan Zipfel, et al. www.thelancet.com Published online October 14, 2013, and Three psychotherapies for anorexia nervosa: a randomized, controlled trial. McIntosh VV, Jordan J, Carter FA, et al. Am J Psychiatry 2005; 162: 741-47

Day Treatment Program: The patient lives primarily at home but spends four to twelve hours per day at a hospital or clinic for individual, group and family therapy sessions and meal support. Typically the patient will eat at least two meals and a snack at the program each day. Day treatment programs may or may not include weekend housing and or support.

Partial Hospitalization (PHP): The patient lives at home but spends six to twelve hours per day, five to seven days per week at a hospital or clinic for individual, group, and family therapy sessions, medical oversight, and meal support. Typically the patient will eat at least two meals and a snack at the program each day Some PHP programs will provide housing and keep a patient overnight for parts of the week.

NOTE: State regulation and licensing will influence whether there are day treatment and/or partial hospitalization programs in your community.

Inpatient (IP): The patient is hospitalized, usually for medical and/or psychiatric stabilization, and may or may not receive therapy. Hospitalization can occur on a voluntary or involuntary basis. Some hospitals have psychiatric beds for involuntarily admitted patients and some do not. Often Inpatient stays take place at a general medical or psychiatric facility which may or may not have a specialized eating disorder unit. Meal support at a general facility usually focuses on medical stabilization (not weight restoration) and may not include regular meal support.

Residential: The patient lives full time at a specialized eating disorder facility where 24/7 care is provided. Residential treatment usually requires a longer-term stay ranging from a few weeks to several months to a year or more. Residential care is usually indicated when outpatient interventions have not been successful at interrupting eating disorder symptoms. The patient needs a highly controlled environment to restore weight, stop binge eating, purging or other self-destructive behaviors.

WHAT SHOULD I KNOW ABOUT MEDICATIONS?

There are no psychiatric medications that cure eating disorders, but several may help with symptoms or with the distress at various stages of treatment. These are some of the things we do know:

- Certain anti-depressant medicines have shown effectiveness with bulimia nervosa, and some medicines have also been helpful for Binge Eating Disorder. Fewer studies have been done in anorexia nervosa.
- Although experts may disagree, some studies suggest certain SSRI's
 and some second generation or 'atypical' antipsychotics may help
 certain patients with anorexia nervosa. SSRI's tend to work best once
 the patient is eating again, as they require serotonin to be made and
 available in the brain before they can do their job. A starved brain
 does not make much serotonin.
- Short-acting anti-anxiety medicines have shown some usefulness in patients with extreme anticipatory meal-time panic, or anxiety when faced with the food in front of them. In addition, medication may benefit a substantial number of individuals who have other 'comorbid' psychiatric conditions, such as depression, anxiety, or Obsessive Compulsive Disorder (OCD), along with an eating disorder.
- The use of psychiatric medications needs to be prescribed and carefully monitored by a psychiatrist who is familiar with the effectiveness of the medication on a malnourished brain and body. It is important for parents to discuss with their care team the pros and cons of specific medicines for their child at various phases of treatment.

The belief that a patient needs to retain their independence and choose to engage in treatment on their own is not supported by the evidence, and the consequences of ignoring or delaying medical and nutritional rehabilitation can be deadly.

EVALUATING TREATMENT OPTIONS

WHAT TRAINING WILL A QUALIFIED EATING DISORDER 'EXPERT' OR 'SPECIALIST' HAVE?

Eating disorder treatment is most often coordinated by mental health providers who come from many different types of academic programs. An academic degree in mental health is a broad curriculum that includes only basic instruction on eating disorders, with more advanced courses offered (depending on the institution) for those with a particular interest. These programs vary enormously in terms of how stringent they are in the supervision of trainees, in their approach to understanding human behavior, treatment approaches, and in the length, content and details of training.

Excellent therapists may be produced by both rigorous university programs that require five years of training, as well as professional schools that have less rigorous selection criteria and require only a few years of training. Still, on the average, those who have five years of training are likely to have learned much more than those with two years of training.

CAN SOMEONE EARN A 'DEGREE' IN EATING DISORDERS?

At this time there is no specific academic program for specializing in the treatment of eating disorders which results in a 'degree' in eating disorders. This means that literally anyone can call him or herself an eating disorder 'specialist' regardless of academic credentials, experience or results. In contrast, a doctor who specializes in treating cancer patients has completed a specific academic program that results in accreditation as an 'oncologist.'

Currently, there is no consensus among medical schools, psychology graduate programs, registered dietician graduate programs, or professional eating disorder organizations as to a minimum required level of training that a provider should have to be considered an eating disorder 'specialist.'

Nevertheless, it is very important to seek a coordinated treatment team that specializes in treating eating disorders. You may have to assemble a team of eating disorder experts if there is not a 'ready-made' team that works together in your area. Such a team will almost always include a psychotherapist and psychiatrist, as well as a family physician familiar with eating disorders. Other team members may be registered dieticians, physical therapists, occupational therapists, etc. It is important to carefully interview providers to learn about their experience, training, and professional alliances. Long experience treating eating disorders is not necessarily a qualification, particularly in a field where the science is changing rapidly. Working with professionals who are trained in evidence-based eating disorder treatments and who are alert to cutting edge research and clinical work is important.

SINCE EATING DISORDER PROFESSIONALS ALL RECEIVE DIFFERENT ACADEMIC TRAINING, IS THERE POST-PROFESSIONAL TRAINING THAT THEY CAN ALL GET THAT IS SPECIFIC TO TREATING EATING DISORDERS?

There are professional organizations that offer continuing education units (CEUs) and/or general 'certification' programs in eating disorders. Each organization, however, has its own curriculum that may, or may not, be based on the latest evidence-based information. Completion of CEUs or certification programs is not equivalent to an academic degree from a university. Rather it is similar to an engineering or architecture graduate becoming certified in "green design" practices, where each certifying organization has their own program and standards.

In addition, there are certificate programs that teach detailed models of therapy that have been developed specifically for treating eating disorders. These are sometimes called 'manualized' therapies because they follow a specific set of treatment principles and stages as outlined in a training manual. Such treatment methods have usually developed out of clinical experience over a long period of time and may or may not be backed up by evidence from controlled clinical research trials or other carefully conducted scientific research.

WHAT QUESTIONS SHOULD WE ASK WHEN EVALUATING A TREATMENT CENTER OR INDIVIDUAL THERAPIST?

Treatment Center:

- Is the program familiar with the 2013 Clinical Practice
 Recommendations for Residential and Inpatient Eating Disorder
 Programs, published by the Academy for Eating Disorders
 (www.aedweb.org)?
- Does the program website explain the program's treatment philosophy and have detailed information about program services, policies and activities?
- Are all staff listed on the website with their credentials, training institution, and professional affiliations?
- Does the program have an acknowledged eating disorder 'expert' who provides regular oversight? What is their training, background, and how long have they worked at the program?
- What is the 'expert's' level of involvement with individual patients, and is their contact information on the website?
- Does the website link to educational resources on eating disorders, best treatment practices and caregiver support services?
- What medical center is the program affiliated with for emergency care?

Clinical Staff:

- Are all clinical staff trained in evidence-based treatment approaches?
- Does the program state who does what therapy, how they were trained to use that therapy, and what evidence is used to show that that therapy works?
- Do clinical leaders have any university affiliations?
- What oversight or peer review is involved in the monitoring of clinical care?
- Does the program have some mechanism for training and supervising their staff?
- How much time per week is devoted to training and supervision?

Program:

 Does the program offer all of the four core components of eating disorder treatment: medical/nursing, nutritional, psychological and psychiatric care services?

- Does the program offer and coordinate between multiple levels of care?
- How are families educated and supported to carry on this work after discharge?
- What procedures are in place for after hours or emergency care? Has this Emergency Room been instructed in how to handle patients with eating disorders?
- Are most staff full-time and are there treatment planning meetings on a regular basis with all staff present?
- Do full-time and part-time staff overlap so that good communication is maintained?
- How will family members or loved ones be involved in evaluation, treatment and meal support?
- What is their policy with regard to involving outpatient providers in treatment and discharge planning?
- Does the program engage in quality improvement efforts? How?
 How is patient and family feedback a part of these efforts?
- Does the program conduct an evaluation of outcomes? Do they have data you can review?

Individual Therapist:

- What is the eating disorder therapist's training, background, and experience?
- Is this person's treatment philosophy and contact information on their web site?
- Does the therapist provide a treatment plan with specific goals and a time line for evaluating progress?
- What is the therapist's approach to nutritional rehabilitation?
- How will family members or loved ones be involved in treatment?
- Does the therapist work exclusively with patients with eating disorders?
- Does this person collaborate with other professionals to create a treatment team? If so, how often and in what manner do they communicate with each other, with the patient and with the family?
- Will the therapist remain involved in treatment if a more intensive level of care is required?
- How does the therapist ensure continuity and coordination of care in preparation for discharge?
- What medical center is the therapist affiliated with for emergency care.

 What procedures are in place for after hours or emergency care? Has this emergency facility been instructed in how to handle eating disorder patients?

DEC

'BEST BETS' FOR FINDING THE BEST CLINICAL CARE:

A clinician who:

- Specializes in treating patients with eating disorders.
- Is trained to deliver appropriate evidence-based treatment for eating disorders.
- Considers family or loved ones as part of the treatment team whenever possible.
- Is able to describe the methods and science behind their treatment interventions.
- Is transparent, non-shaming, welcoming of and responsive to patient and family feedback.
- Admits errors or lack of knowledge and makes efforts to get answers.
- Works as part of a multi-disciplinary team.
- Has child and adolescent subspecialty training.
- Is an active member of a professional eating disorder organization.

A program that:

- Offers several different levels of care.
- Is hospital- based or allied with a hospital- program sponsor.
- Employs team members with a high-average years of study, specialized training, and experience.
- Staff is all or mostly full-time rather than part-time. Educates all staff
 members about eating disorders and how to be sensitive to the needs
 of patients and families.
- Offers a higher percentage of treatment hours spent with more trained clinicians.
- Uses a differential diagnostic procedure² and complete psychiatric/psychological assessment during evaluation, including: family history, developmental history, personality traits, the patient's likes/dislikes, strengths and limitations, etc.

² The systematic process of differentiating between two or more conditions that share similar signs or symptoms.

- Will help you understand and consider various treatment options to find the best match for the patient and family.
- Is willing to refer to another treatment provider if they feel they cannot provide the most appropriate treatment.

'RED FLAGS' WHICH MAY INDICATE A CLINICIAN IS NOT USING THE MOST UP-TO-DATE TREATMENT:

- Has a general psychiatric or medical practice not specializing in eating disorders.
- Dismisses concerns about medical stability or physical symptoms.
- Does not address nutrition and eating behaviors.
- Does not include family members in the assessment.
- Does not view caregivers as part of the treatment team.
- Does not actively involve family members in the patient's therapy and recovery plan.
- Is not familiar with changes in treatment approaches and research from the past five years.
- Focuses therapy on addressing "underlying causes," family dysfunction, or "control issues" instead of behavioral interventions.
- Is dismissive of team approach, biology, or evidence-based treatment.
- Makes general statements about "all" patients, or "all" families
- Treats children or adolescents but is not trained in Family-Based or Maudsley outpatient treatment.
- Is not trained in Cognitive Behavioral Therapy.
- Uses one treatment approach for all patients.
- Promises fast, easy treatment.
- Promises all or most patients can be cured by their treatment approach.
- Refuses to refer the patient to other treatment providers even when progress is not being made.

APPENDIX: COMMON CREDENTIALS FOR EATING DISORDER PROVIDERS - DEGREES, LICENSES & CERTIFICATIONS

For a more complete list see: http://feast-ed.org/TreatingEDs/Initials.asp

APRN: Advanced Practice Registered Nurse (an RN with post-graduate education in nursing)

ATR: Art Therapist Registered

BC: Degree extension for

'Board Certified'

CASAC: Credentialed

Alcoholism and Substance

Abuse Counselor

CEDS: Certified Eating
Disorder Specialist - A
certification offered by the
International Association of

Eating Disorder Professionals

(IADEP)

CNC: Certified Nutrition

Consultant

CNS: Certified Nutrition

Specialist

Counselor: A generic term for

someone who counsels

DCSW: Doctorate in Clinical

Social Work

DNP: Doctor of Nursing

DO: Doctor of Osteopathic Medicine - A professional

doctoral degree for physicians and surgeons offered by medical schools in the United States.

Dr.: Doctor could be an M.D, a Ph.D., a Psy.D., Ed.D., D.O., or

a DCSW

EdD.: Doctorate of Education

FAAFP: Fellow American Association of Family Practice **FABMPP:** Fellow American

Board of Medical Psychotherapists & Psychodiagnosticians

FADA: Fellow of the American

Dietetic Association

FAED: Fellow of the Academy

for Eating Disorders **FIPA:** Fellow of the

International Psychoanalytic

Association

FSAM: Fellow Society for

Adolescent Medicine

FNP: Family Nurse Practitioner **LCAT:** Licensed Creative Arts

Therapist

LCSW: Licensed Clinical

Social Worker: A mental health professional with a Masters Degree (MSW) in social work and two years of supervised

clinical experience.

LCSW-C: Licensed Certified

Social Worker - Clinical: Master's in Social Work,

Clinical

LMHC: Licensed Mental

Health Counselor

LMSW: Licensed Master

Social Worker

LN: Licensed Nutritionist

LPC: Licensed Professional Counselor: A type of counseling license generally held by a Masters level graduate or professional.

M.A.: is a Master of Arts. May refer to any discipline.

MAEd: Masters Degree in Education

M.D.: A Medical Doctor or Physician (May have a specialization in: Adolescent Medicine, Pediatrics, General Psychiatry, Family Practice, or Internal Medicine)

MSW: Masters in Social Work (May have a specialization such as psychiatric social work, or child and family counseling)

MSN: Master of Science in Nursing

NP: Nurse Practitioner (an APRN who has completed advanced didactic and clinical education beyond that required of the generalist RN role)

NPP: Nurse Practitioner in Psychiatry

Ph.D.: Doctor of Philosophy - any discipline. A doctoral degree requires extended graduate level university training. This training generally lasts 4-6 years after completing regular college bachelor degree programs.

PMHNP: Psychiatric Mental Health Nurse Practitioner

PMHCNS: Psychiatric Mental Health Nurse Clinical Specialist

PNP: Psychiatric Nurse Practitioner

Psychiatrist: A Medical Doctor or Physician (M.D.) who has completed a multi-year residency in Psychiatry (May have a specialization in: general psychiatry, child or adolescent psychiatry

Psychoanalyst: A therapist who practices analysis and focuses on early childhood experiences.

PsyD: Doctor of Psychology **Therapist or Psychotherapist:**This is a generic term and does not apply to any specific credentials.

RC: Registered Counselor RCC: Registered Clinical

Counselor

R.D.: Registered Dietician



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