



EATING DISORDER FOUNDATION  
OF NEWFOUNDLAND AND LABRADOR  
HOPE ALWAYS

## Understanding Eating Disorders



# What is an Eating Disorder?





# What is an Eating Disorder?

- An eating disorder is a ***coping strategy*** that an individual uses to deal with ***deeper problems***. It is a ***complex situation*** in which food, eating and body image difficulties become the language through which a person's concerns about themselves are expressed. Eating disorders are usually characterized by an ***intense fear of weight gain, feelings of ineffectiveness and low self-esteem***. Eating disorders are serious health disorders in which a person may experience emotional, psychological and social difficulties as well as physical complications.



## **...Disordered Eating!**



- **Anorexia nervosa**
- **Bulimia nervosa**



# Anorexia Nervosa

- a self-starvation disorder. The anorexic (the person afflicted with anorexia) ignores hunger, restricts the amounts and kinds of food eaten to such an extent that starvation is a very real possibility – as is death.





# Bulimia Nervosa



- A binge-purge disorder. The bulimic (the person afflicted with bulimia) gorges (binges) on enormous amounts of food – sometimes thousands of calories at one time – and then gets rid of it (purges) by vomiting, excessive use of laxatives, or other means. Bulimia is also dangerous to a person’s physical and mental health.



# **Irreversible ( Permanent) Complications**

- Brain Shrinkage (“Atrophy”)
- Bone Thinning ( “Osteoporosis”)
- Cardiomyopathy (weakness and enlargement of the heart)



# Some Causes of an Eating Disorder

- Biological – can run in families – genetic factors.
- Low self-esteem and negative body image.
- Inability to cope with emotions – identity concerns.
- Society reinforces the idea to be happy, successful and healthy we must be thin.
- Adolescents, in particular, are most vulnerable influence of peers, role models, the school climate and media.



# Some Causes of an Eating Disorder...

- Sexual and physical abuse and controlling relationships.
- High achievers – tend to be perfectionists.
- Can be a coping strategy used to deal with deeper problems.
- High-risk activities/sports, where judgments of performance and success are based on body size and shape.
- Family issues the person suffering from an eating disorder has difficulty coping with.



# Signs of an Eating Disorder:

- Weight loss – very thin
- Excessive exercise
- Fear gaining weight
- Refuses to eat with families and friends
- Constantly thinking about food
- Isolate themselves from family and friends
- Secretive about food – lie about eating
- Binge secretly
- Overly concerned about appearance
- Mood – Personality changes



# Did you know?

- Approximately 7500 individuals in NL are at risk of having an eating disorder.
- 10% -15% of adolescents are affected (13-22).
- Low level of understanding by public.
- Mortality rate can be as high as 20% if not treated early.
- Significant irreversible health complications if not treated early.
- Similar if not the same treatment and support issues exist in all Provinces
- Affects 1.5% to 2.0% of population



# Did you know?

- High levels of eating disorders amongst post secondary students.
- 80% of those who develop eating disorders are women while 20% are men.
- Eating disorders are now the third most common chronic illness in adolescent girls.
- Eating disorders exist in all age, racial and ethnic groups. You cannot tell if someone has an eating disorder just by looking at them.
- ED rates in NL are higher than PEI, NB, MB, SK, AB, BC and the same as ON, QC, and NS



# Supporting Eating Disorders as a Lifestyle

***There are currently 26 websites that we know of promoting eating disorders as an acceptable lifestyle.***

- Giving in to food shows weakness, be strong, and you'll be better than everyone else
- Perfection doesn't include food.
- Starving makes me pretty.
- Please, do not feed the models.
- I want a perfect body, I want a perfect Soul, I don't care if it hurts- I want to have control.



# Recent Research (U.S.A 1999-2006)

## Hospitalization for Eating Disorder Persons between 1999-2006

This information was gathered from a database of important records and research conducted by the Agency for Healthcare Research and Quality in Rockville Maryland. It's another piece of research that confirms the growing rate of eating disorders and the profound impact they are having on families.

- **Number of Men and Women increased 18%**
- **119% increase for children under 12 years of age**
- **48% increase for men and women age 45 to 64**
  - **37% increase for men**
- **Women continue to dominate at 89%**



# Current Treatment Programs: Children

- Janeway Adolescent Medicine Team
  - medicine, psychology, social work, dietician, nurse practitioner
  - Children & Adolescents up to age 18
  - In patient beds, out patient program
  - *Weakness: insufficient human resources to provide adequate intervention*
  - *Continuity referrals to new Center for Hope now available*



# Current Treatment Programs: Adult

- **Provincial weakness / overall lack of specialized Eating Disorder Treatment Programs**
- Long waiting lists for access to available professionals particularly outside St. John's.
- Individuals on waiting list either have few therapy options if uninsured, or those insured forced to try to find private therapists outside (lack of therapists with ED expertise)
- New Center for Hope in St. John's is a provincial program that is available for those over 15+ and is a good specialized eating disorder treatment program.



# Benefits of Early Detection and Early Intensive Treatment

- Reduces morbidity & mortality
  - Up to 20% mortality in long term studies
- Earlier more intensive treatment more successful and necessary for recovery



# Prognosis

- ~ 45-50% improve to good health, good outcome
- ~25-30% struggle to keep themselves out of hospital & often have irreversible complications, chronic fluctuating course
- ~ **25% poor outcomes,**
  - **Up to 20% mortality**
  - **irreversible complications universal**
  - **multisystem organ failure and death**



# What do I do if I think I have an Eating Disorder?

***It is important to get help***

- Eating Disorders can be treated successfully and professional help is always required.
- First step in overcoming an eating disorder is to recognize and acknowledge the problem.
- Recognize that you need help and that you cannot “do it alone”.
- Early treatment is an essential component of recovery and has been shown to be more successful.
- Discuss your eating disorder with family members and close friends who will want to support you.



# What do I do if I think I have an Eating Disorder?

- Acknowledge that medical attention is critical for proper diagnosis and ongoing health monitoring.
- Be informed and educate yourself on the facts about eating disorders. Attend public forums.
- Eating disorders don't "go away"; experienced help is required for full recovery.
- Consult your Eating Disorder Foundation for advice, information and support.
- If you are not satisfied with the help you receive do not be discouraged, seek out more help.



# Recommendations

- EH Eating Disorder Working Group based upon literature reviews, site visits/ consultations, focus groups, questionnaires and expert consensus recommended:
  - Establishment of an **Intensive Outpatient Day Treatment Program**
  - Free standing/designated space for clinic/program
  - Embedded within Mental Health and Addictions Program

EATING DISORDER FOUNDATION  
OF NEWFOUNDLAND AND LABRADOR  
HOPE ALWAYS





# Mission

- The Eating Disorder Foundation of Newfoundland and Labrador (EDFNL) is ***a leadership advocacy group*** dedicated to promoting research and providing public support services and information about matters related to eating disorders, including information on available treatment services for individuals and families who experience disordered eating.



# Goals of EDFNL

- **To support** persons who experience disordered eating by acting as a Resource Centre and a front door to a focused and coordinated treatment path.
- **To promote** a healthy body image and self-esteem by way of public education and awareness programs
- **To advocate** at various levels of government, health and community groups to ensure input and involvement in the decision making processes that affect eating disorder policies and treatments
- **To educate** individuals, professionals, government and families through the distribution of materials, an information line, regular awareness programs and a living website
- **To advocate** for and support ongoing research and related medical services



# Status of Foundation

- Established November 29, 2006
- Incorporated
- Charitable Tax Status in place
- Business office open (fully equipped)
- Website developed – [www.edfnl.ca](http://www.edfnl.ca)
- Board of Directors in place
- Fund Raising in progress (fundraisers and pledges)
- Primary objectives advocacy and awareness (have realized major successes in these areas.)
- Improved Family Support Services (a critical issue)



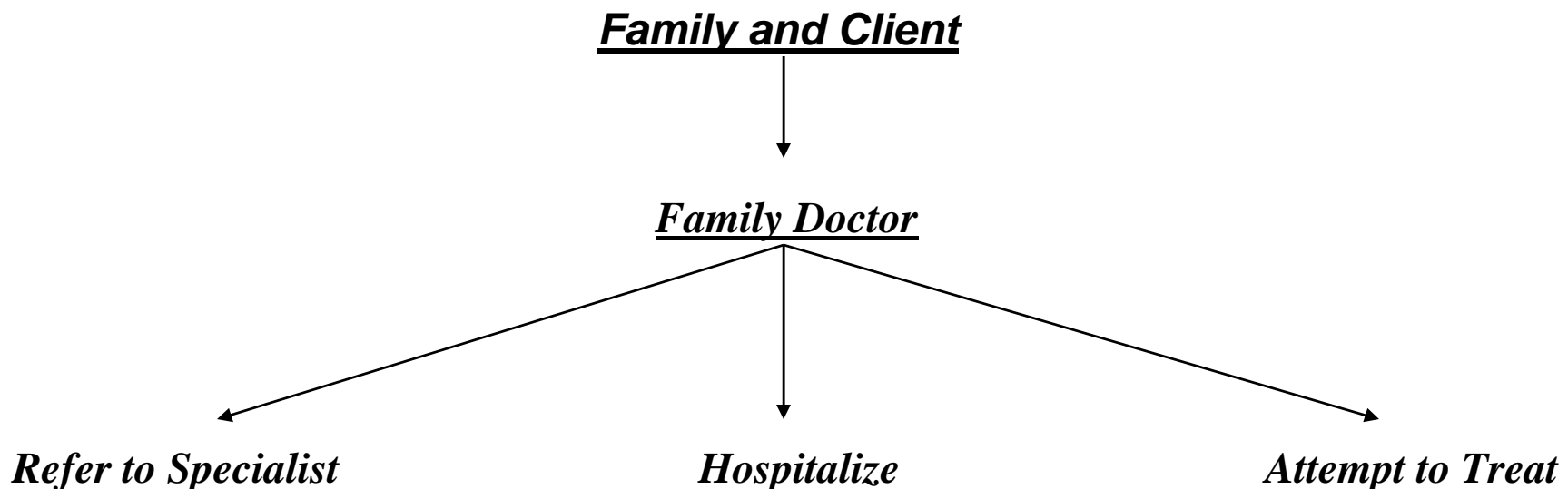
# Some Services Provided by Foundation

- Education and Awareness Programs
- Eating Disorder Awareness Week events
- Public Meetings, Seminars, speaking events (26 in total to date)
- Front door for Eating Disorder families
- Literature (Brochures)
- Materials Resource Center (80 publications, DVD's etc.)
- Handling many calls from public (400 calls over 2 years) (Advice and support)
- Advocacy (Government-Public-Healthcare)
- Scholarships
- Website established
- Support and partners with new Centre for Hope
- Families Supporting Families support group meetings
- Quarterly Newsletter
- Informational Bulletins
- Initiating and leading action for National and Atlantic Canada Working Groups



# Today's Treatment Process

- Early detection opportunities being missed (most critical)
  - Specialist referral result in long waiting periods
  - Families are not receiving much support





# Future Treatment Processes

Family & Client

Family Doctor

Eating Disorder Foundation

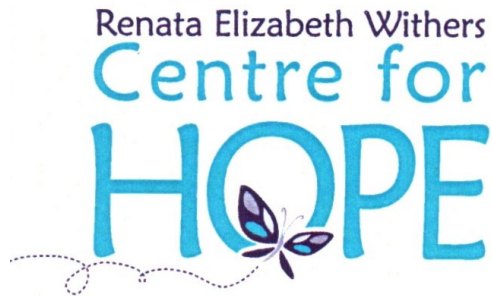
Center for Hope

Can Provide:

- Hand Holding
- Someone to talk to
- Literature
- Educational materials and programs
- Networking – other families
- Advice
- Advocacy (speak for)
- Acts as Traffic Cop

Can Provide:

- Treatment
- Treatment protocols
- Meals
- Professional Staff
- Health assessment
- Follow-up service
- Individual and group therapy
- A more responsive service
- Professional Referrals



# Renata Elizabeth Withers Center for Hope Clinic

- Center announced in 2006 Provincial Budget
- Funded for 2008 and onwards
- Day programs – 5 days/week (11 hours per day)
- Provincial Mandate
- Wellness Model (promotion, prevention and early intervention)
- Treats and supports outpatients and families (wholistic approach)
- Serves adolescents and adults – 18+
- Referrals from family doctor or similar healthcare professional mandatory
- New Center opened in June 2009 (operated for a year in temporary quarters)
- Provides continuity in treatment and support services e.g. relapses



# Center for Hope Clinic

- Will provide 3 meals, 2 snacks per day (food therapy)
- Intensive group/individual therapy
- Close liaison with Child Health and Adult Medicine Program  
→ Admission for medical stabilization
- Staff of 10 to 12 professionals
- Provides treatment continuity (other programs, relapses etc)



# Interdisciplinary Team for Centre

- Nurse Practitioner
- Nurse
- Adolescent Psychologist
- Adult Psychologist
- Dietician
- Social Worker
- Occupational Therapist
- Physiotherapist
- Psychiatrist
- Pediatrician
- Medical Internist
- Teacher for the patients in school
- Food Services Supervisor



# **Developing Community Capacity to Help Families**



Eating Disorder Interprofessional  
Community Capacity Building Program

# Community Capacity Building Project

- We have learned about the needs of the families
- The experiences of working with families in groups, seeing them evolve into advocates for services for clients and for families
- Decrease the isolation experienced by families
- Decrease isolation experienced by professionals
- Allow community service providers to learn what to say to families, how to include them in the treatment in a meaningful way
- Enable clients to receive treatment in/near their home communities



Eating Disorder Interprofessional  
Community Capacity Building Program

# Summary: Lessons Learned

- Importance of involving consumers in service planning and evaluation
- Recognition of non-specialized professionals as main resource in treating ED's
  - Importance of supporting them in their work with ED's
- Importance of sensitizing professionals to the importance of family education and support even with adult clients



# Parents of HOPE

- Meets monthly for support for parents who have completed the Bridge to Hope group
- Parents choose the frequency of attendance they are comfortable with
- Meetings are held during every month of the year



# Parents of Hope: Essentials

- Health professional facilitator with mental health and group training
- Core group of parents who attend regularly
- Ability to accept where parents are in their evolution
- Facilitator must be a supporter of “family”
- The facilitator committed to the group for an indefinite period



# Body Image Network

- A group of organized volunteers and professionals with healthcare expertise
- Developed curriculum for grades 2 & 4 across Province
- Addresses wellness, self esteem, positive body image, positive lifestyle etc.
- Hopeful to have materials included in standard school curriculum soon



# Summary

- Bridge to Hope (education) and Parents of Hope (support) provide support services for families
- Bridge and Parents of Hope powerful interventions for families
- Need to replicate these services for other families across the province (Corner Brook and Labrador City have started community support groups)
- EDFNL as official advocate for ED's to government in partnership with Eastern Health and families
- Eating Disorders are rampant in NL (and across Canada)
- Awareness is the #1 challenge



# Pressing Needs and Priorities

## Long Term Issues

- ***More early diagnosis at the family doctor level (a major area of concern) (currently the #1 priority)***
- A lot more awareness (remove stigma)
- Substantially improved access to healthcare specialists (waiting times very long)
- More training and education within Health Boards for major hospital locations
- Wellness and prevention models for schools and PSE's
- Healthcare professionals (schools) high priority in curriculum
- Continue strong advocacy
- Public education and related materials, the highest priority



# A lot of Progress is Happening

- EDFNL firmly established and are now interacting with families and healthcare system
- New Center for Hope established June 2009 – a very good treatment and support program
- Awareness Programs working – ED people are coming forward in large numbers earlier, Stigma diminishing
- Increased momentum about ED issues finally being recognized by the public and healthcare system
- Community Capacity Building Model in progress for provincial mandate and roll out
- EDFNL has held 26 Public Meeting events this past year (1500 people in attendance)
- Education improving at all levels of stakeholders



# Our Ongoing Team Response to Eating Disorders

<u>Group</u>	<u>Responsible for</u>
Government of NL Department of Health	Provided budget for new Outpatient Intensive Treatment Centre
Eastern Health	<ul style="list-style-type: none"><li>•Manages new Centre and Treatments</li><li>•Provide professionals for Centre</li><li>•Janeway Eating Disorder Program</li></ul>
Eating Disorder Working Group (Eastern Health)	<ul style="list-style-type: none"><li>•Coordinates Eating Disorder activities within Eastern Health</li><li>•Responsible for Community Capacity Building (CCB)</li><li>•Professional Group</li></ul>



# Our Ongoing Team Response to Eating Disorders continued...

## Group

Eating Disorder Foundation of NL

## Responsible for

- Provincial mandate
- Awareness
- Education
- Family Support Services
- Advocacy
- Board (mix of public and healthcare)



Renata Elizabeth Withers  
Center for Hope

- Fully staffed and dedicated Centre
- Open June 2009
- A major breakthrough
- Oversight Advisory Counsel in place



# Our Ongoing Team Response to Eating Disorders continued...

<u>Group</u>	<u>Responsible for</u>
Body Image Network	<ul style="list-style-type: none"><li>•Developing curriculum for schools etc.</li><li>•Wellness and Prevention model</li></ul>
Parents of Hope St. John's	<ul style="list-style-type: none"><li>•Families organized to support families</li><li>•Model to be used across the province</li><li>•Training and orientation for participation</li></ul>



- All 7 groups are working together and coordinating projects – Best efforts model
- We are all interrelated and while mandates differ somewhat, we collectively are focused on the core issue for Eating Disorders, awareness, prevention and treatment.



# Contact Us

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