

# Eating Disorder Services:

## The Reality of Care and the Urgent Need for Reform

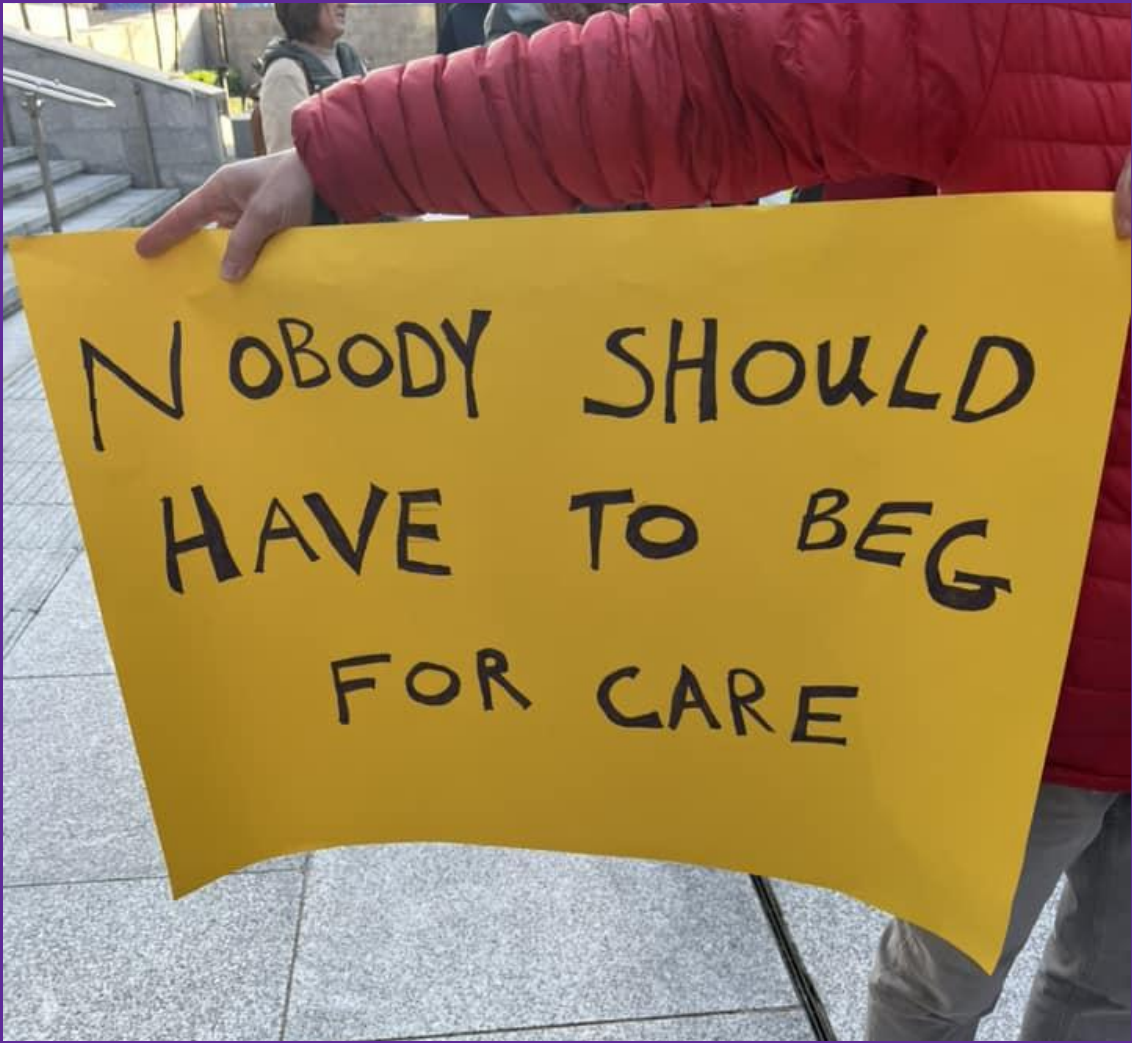
By Mind EveryBody

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[mindeverybody.com](http://mindeverybody.com)



# Introduction



A person wearing a red puffy jacket is holding a bright yellow rectangular sign. The sign has black handwritten text that reads "NOBODY SHOULD HAVE TO BEG FOR CARE". The person is standing on a paved sidewalk, and a set of stairs is visible in the background. The entire image is set against a solid purple background.

NOBODY SHOULD  
HAVE TO BEG  
FOR CARE

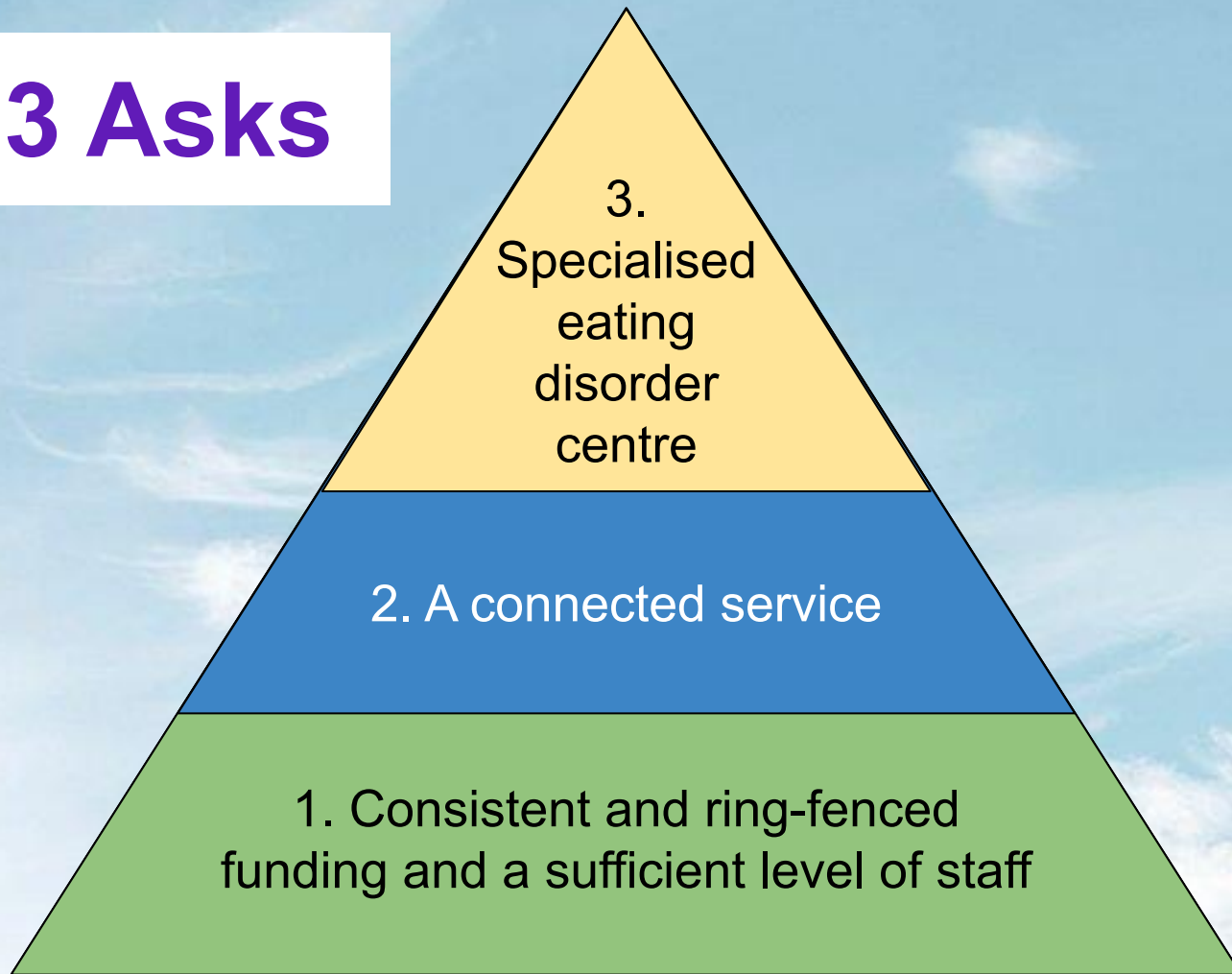
# Goal:

A commitment from all political parties to support improvements in services.

**STRONGER  
TOGETHER**

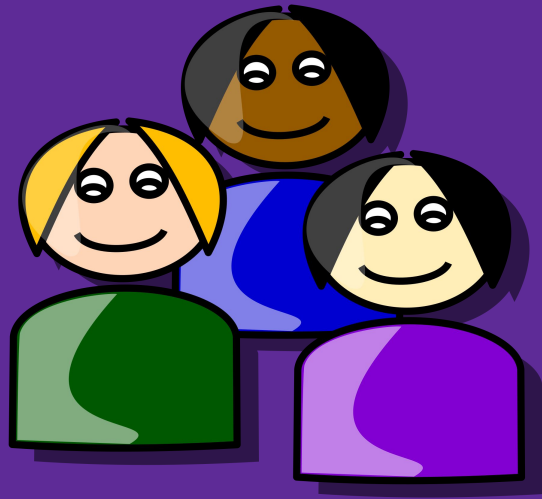


# Top 3 Asks



# Who do you think has an eating disorder?





The answer is all of them.

But how can you tell?

You can't.

Because eating disorders affect males and females,  
and individuals of all ages. There is no typical  
appearance. No eating disorder presents the same.



Also, eating disorders are  
classified as a

mental illness.

So no matter how someone  
appears, we cannot tell their  
inner struggles just by looking.

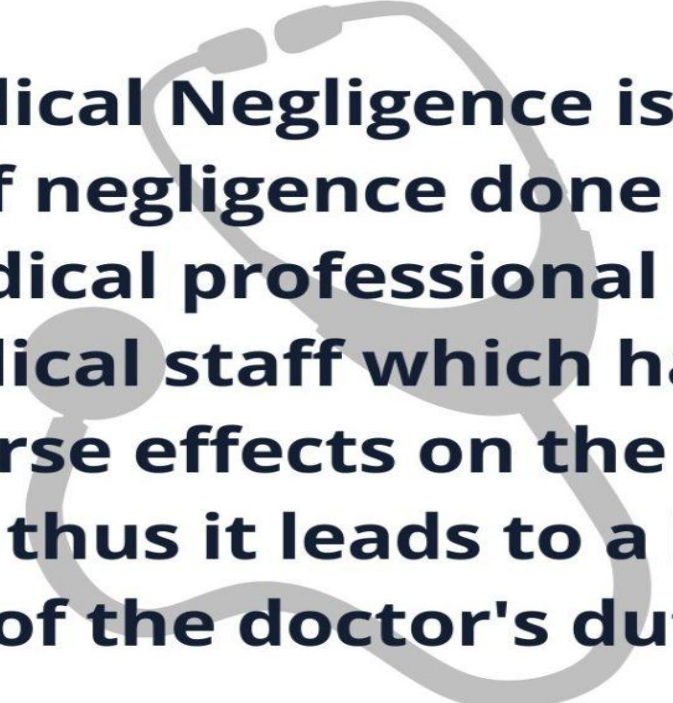


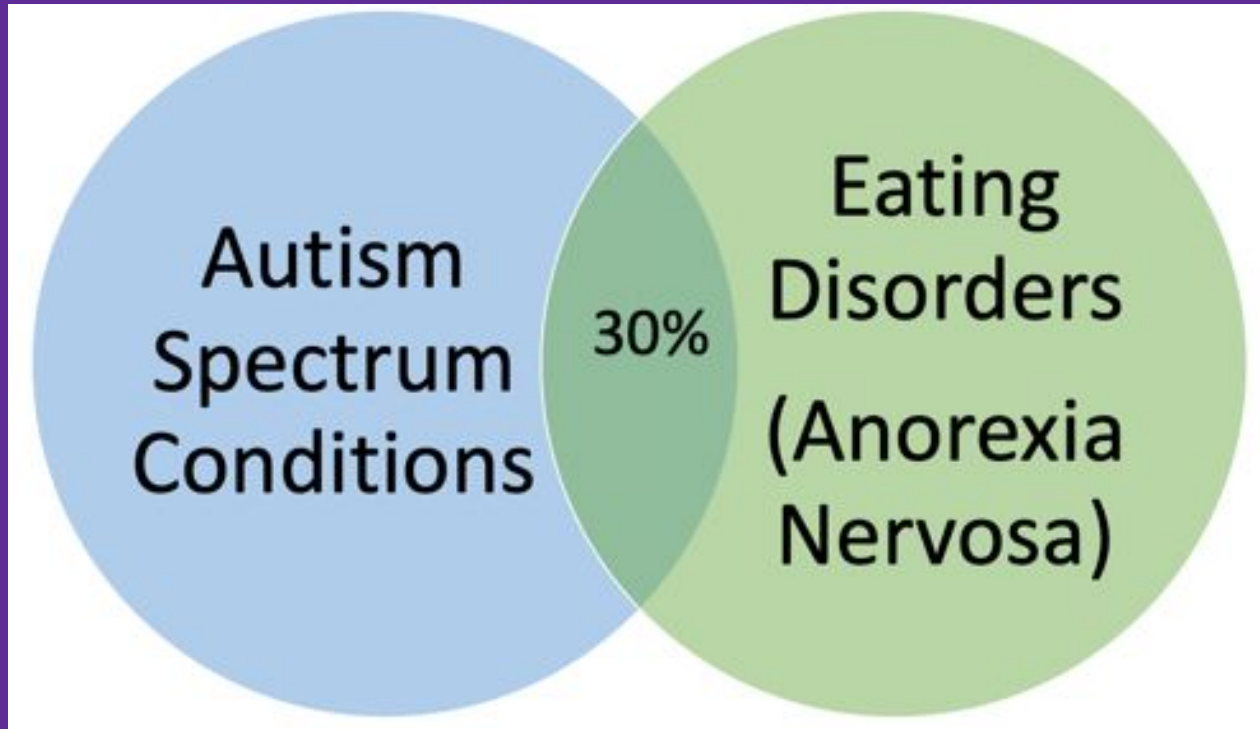
# Luna



# **Meaning of Medical Negligence**

**Medical Negligence is an act of negligence done by a medical professional or any medical staff which has very adverse effects on the patient and thus it leads to a breach of the doctor's duty.**







# MENTAL HEALTH & EATING DISORDER STATISTICS



EATING DISORDERS AND MENTAL ILLNESSES  
COMMONLY OCCUR TOGETHER.

ONE STUDY OF PEOPLE  
HOSPITALIZED FOR AN  
EATING DISORDER FOUND THAT

97% • 

HAD AT LEAST ONE CO-OCCURRING  
MENTAL HEALTH DISORDER, WITH

 • 94%

SUFFERING FROM MOOD DISORDERS  
LIKE MAJOR DEPRESSION

1/3 • 

OF PEOPLE WITH BINGE  
EATING DISORDER ARE  
ALSO DIAGNOSED WITH  
MAJOR DEPRESSION

69% • 

OF PATIENTS WITH  
ANOREXIA NERVOSA  
ALSO HAVE OBSESSIVE-  
COMPULSIVE DISORDER

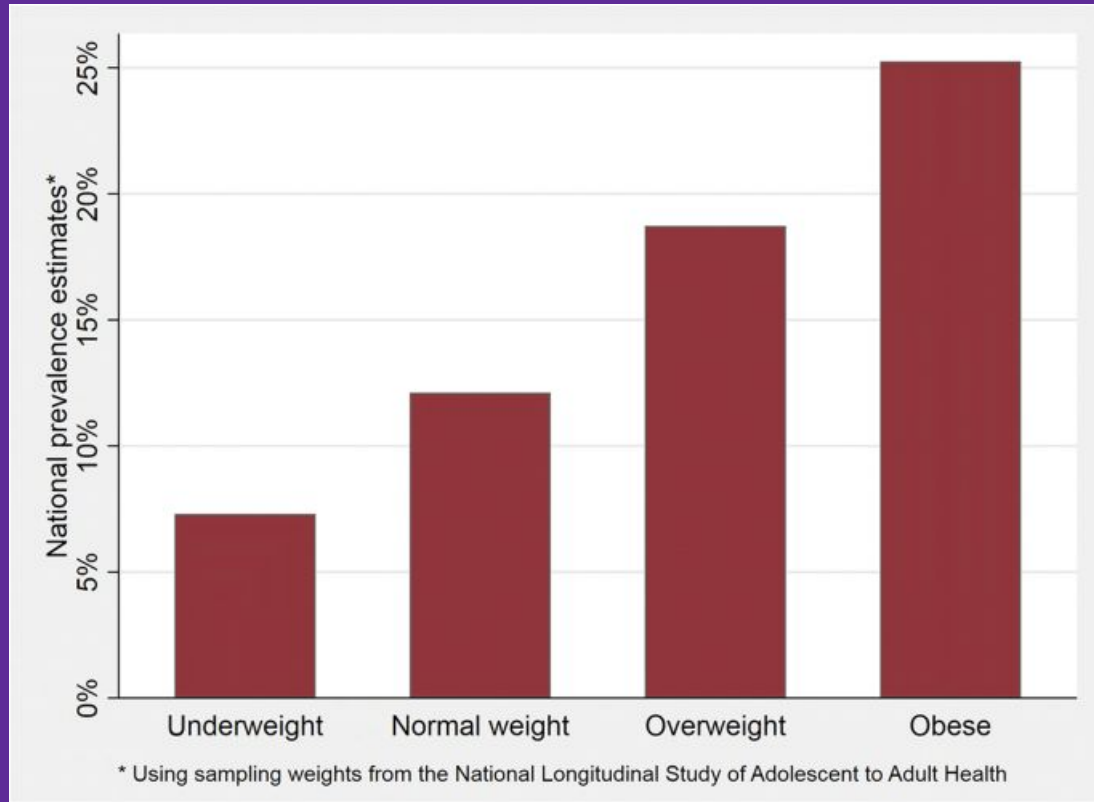
81% • 

OF PEOPLE WITH BULIMIA  
NERVOSA ALSO HAVE  
AN ANXIETY DISORDER

1/4 • 

PEOPLE WITH AN EATING  
DISORDER ALSO HAVE  
SYMPTOMS OF POST-  
TRAUMATIC STRESS DISORDER





The prevalence of eating disorder behaviours by weight groups



# Amy

Founder of the Mind EveryBody  
advocacy group

### UK Model:

“The **standard** is for treatment to be received within a **maximum of 4 weeks** from **first contact** with a designated healthcare professional for routine cases and **within 1 week for urgent cases.**”

Access and Waiting Time Standard for  
Children and Young People with an  
Eating Disorder.  
NHS England, July 2015

### Irish Model:

“Recommended timeframes:

**Assessment** within **2-4 weeks** depending  
on the clinical severity and risk in the  
individual case

**Treatment starts** within **2-4 weeks** of  
assessment.”

HSE Eating Disorder Services  
Model of Care  
(2018)

# Ask: More Staffing and Funding



To provide early and immediate supports to parents:

- Information/training courses/education courses
- Meal coaching
- List of literature or support services provided

and sufferers:

- No waitlists
- Therapy
- Meal supports



# Admission Denials from CAMHS Inpatient Units

- Not clinically appropriate
- Not in catchment
- Not eating orally
- Won't benefit from an inpatient stay
- Should be discharged to community care



# Admission Denials from Private Inpatient Units

**DEAD END**

- Not eating orally

# Begging for help

Complaints submitted to:

- HSE
- Ombudsman for Children
- Linn Dara
- TDs



Result: No resolution, remained in children's hospital

# Last Resort: Media

The Journal Irish News FactCheck Voices Climate European Electio



Amy Hanley,

CAMHS CRISIS

## Dublin mother of teen hospitalised with anorexia says family are 'caught in a trap'

Mother of a girl hospitalised with anorexia after year long wait to see CAMHS says she doesn't know where to turn.

# Specialised Eating Disorder Centre

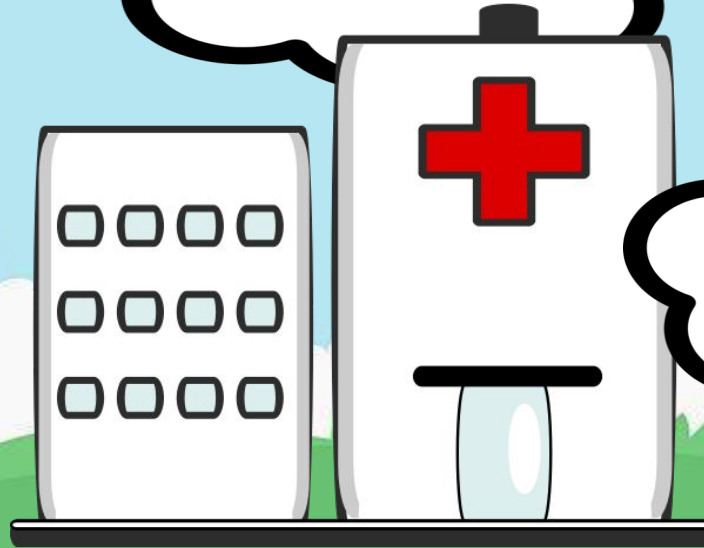
Continuity of care

Holistic treatment

No catchment  
restrictions

More efficient use  
of funding

Specialised  
staff



# Comments from Professionals

It's just some fruit,  
there's barely any  
calories in there.

You look healthy.

You're not even trying.  
You're taking up a bed  
someone else could have.

You're setting a bad  
influence for other patients  
when you don't eat.

You look well.

You don't look like you  
starve yourself.

You're not here to not eat.



What was your highest,  
lowest, and current weight.



In **Ireland**, the STEDI **study** found that even experienced **health professionals** with **moderately good knowledge of EDs** show **poor recognition** of the symptoms and tend to view EDs as a group of chronic, female-based conditions.

HSE Eating Disorder  
Services Model of Care  
(2018)

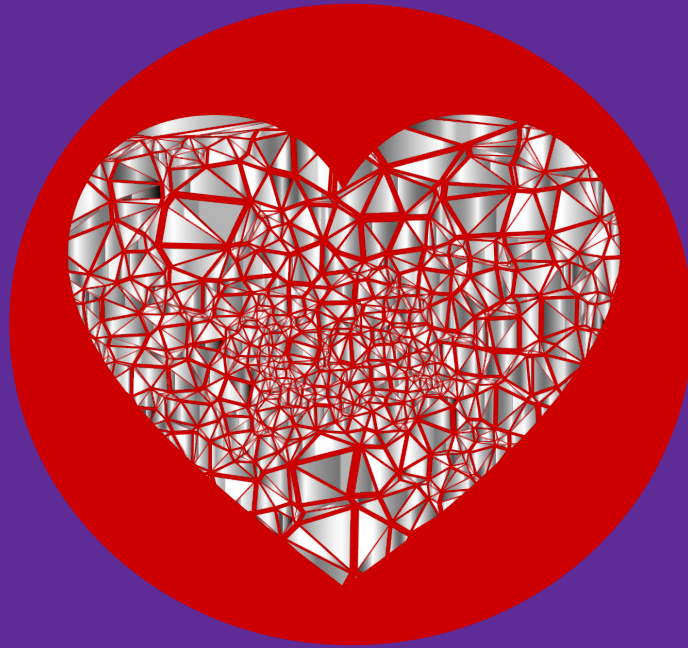
# Effect on Family

Try to maintain job

Constant traveling  
to hospital or  
appointments

Less time with other  
children

No time for self-care



Constant survival mode

No concentration

Unpaid leave

Carer's Benefit

Cost for private therapy

Stress and depression

# Conclusion

“When a flower  
doesn't bloom, you  
fix the environment  
in which it grows,  
not the flower”



# Deirdre Reddan

- Co-founder Supported Families
- Parent Coach/Mentor
- Master Practitioner in Eating Disorders
- Advanced Diploma in Coaching
- Member of International Association of Eating Disorder Professionals





ISOLATION  
GUILT  
CRISIS  
ANXIETY  
DENIAL PAIN  
OVERWHELM  
EMBARRASSMENT

UNCERTAINTY





# BODYWHYS

The Eating Disorders Association of Ireland

Jacinta Hastings  
Chief Executive Officer

# How does Bodywhys support people affected by eating disorders?



## The value of lived experience and clinical training in creating a safe service

- Established in 1995 by a group of parents
- Started as a small support group
- Evidence-based support services run and supervised by fully qualified psychotherapists and clinical psychologists
- Trained volunteers (74)
- Lived experience (Self experience and parents)

## Eating Disorders in Ireland

- 188,895 (Sharing the Vision)
- 1,757 new cases per year
- Covid-19 Impact
- Child & Adolescent (u-18) admissions tripled in last five years (HRB)

# How do we provide a safe and professional service?

- Recovery policy
- Eating disorders are complex illnesses and people have varied and different experiences
- Support Ethos: We understand that an eating disorder is not just about food and weight



## SUPPORT SERVICES

Anyone who access our services, including children and young people, have the right to be consulted, protected and treated with respect.



HELPLINE: (01) 2107906



EMAIL SUPPORT



ONLINE SUPPORT GROUP:  
BODYWHYSCONNECT 18+



ONLINE SUPPORT GROUP:  
YOUTHCONNECT 13-18



FREE PILAR PROGRAMME  
FOR FAMILIES



VIRTUAL SUPPORT GROUPS  
(18+)



## How people contacted us in 2023:

Origin of support queries	Contacts by service	
Admin Email and Phone	204	
Helpline	1,292	
Email Support Service	2,346	
Online Connect Groups	620	
Virtual Support Groups	347	
Family Support Package	1,106	
<b>Total</b>	<b>5,915</b>	

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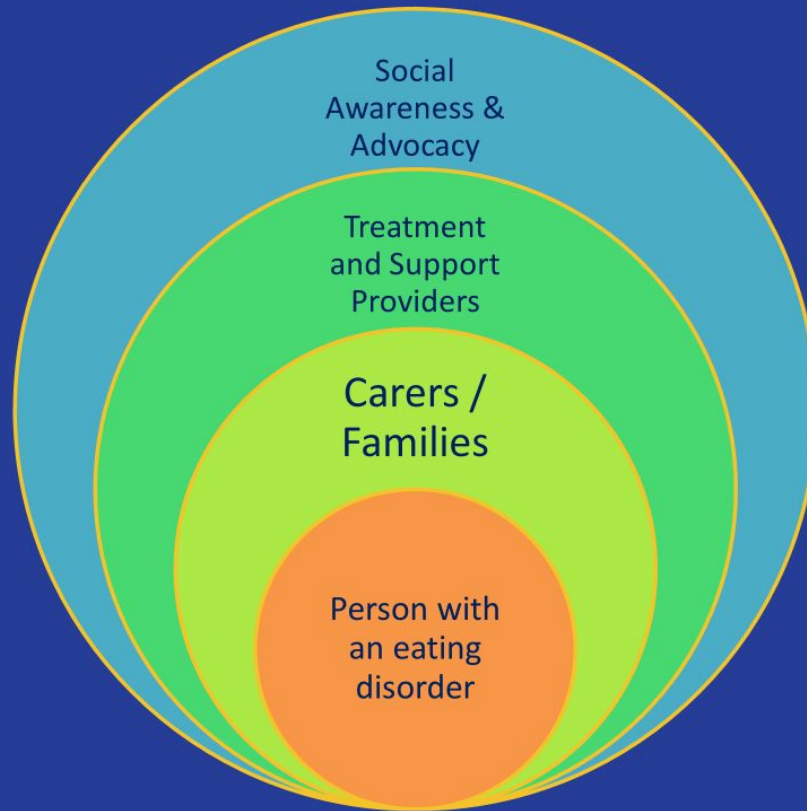
ONLINE SUPPORT GROUP:  
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FREE PILAR PROGRAMME  
FOR FAMILIES



VIRTUAL SUPPORT GROUPS  
(18+)



# Family Support Package

## **Part 1 : PiLaR Family Support Programme**

Structured 4-week programme x 637 attendees in 2023

## **Part 2 : Post- PiLaR Support Group**

3 times per month : facilitated

## **Part 3 : New Maudsley Carer Skills Workshop Series**

Carers of PWED report high burden of care

# Family Support Package

## **Part 4 : Regular Maudsley Group**

Ongoing once a month combines support with skills practice

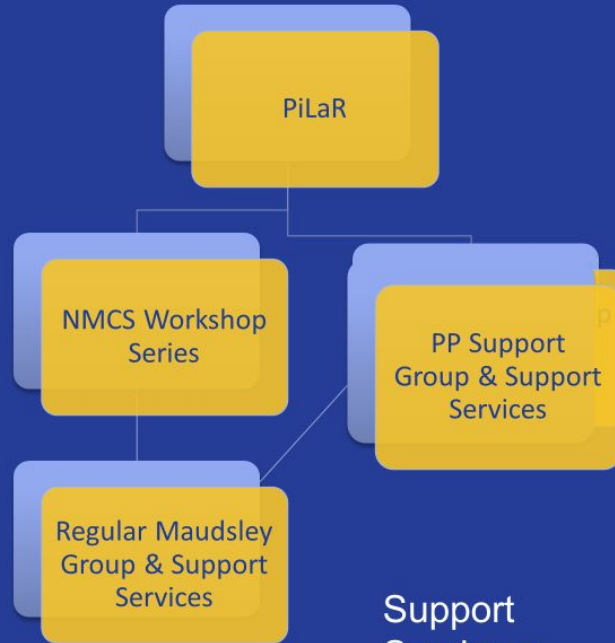
## **Part 5 : 2-Day Parent/Carers New Maudsley Skill-Based Course** **Intensive 2-day skills-based course**

In 2023, we ran the PiLaR 4-week programme 5 times, with 637 people signing up to attend.

Month	PiLaR Attendance
January	115
March	103
May/June	134
September	182
November	103
<b>Total</b>	<b>637</b>

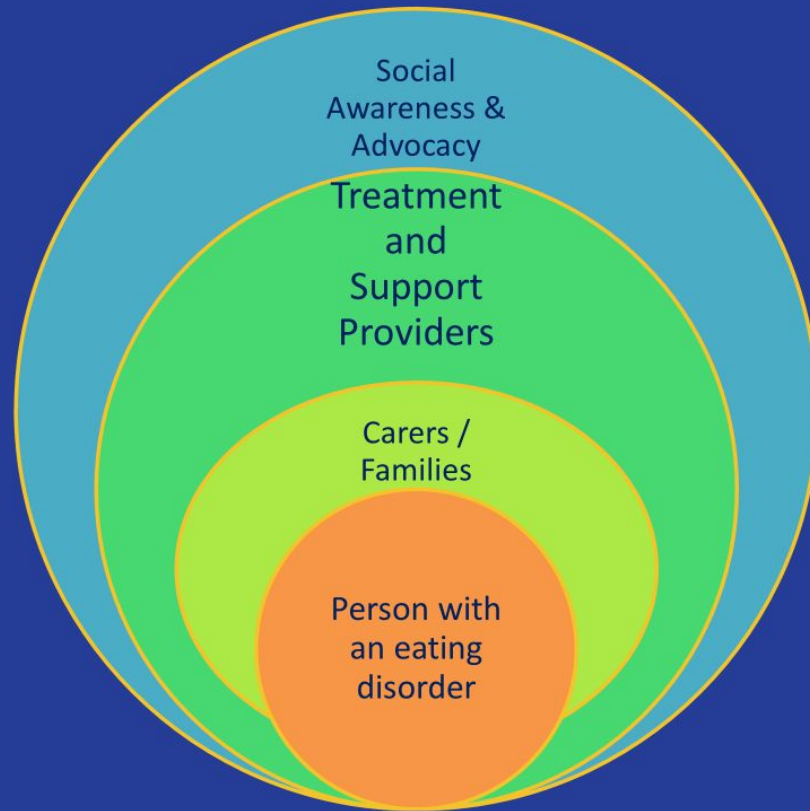
## Other Supports:

- Website
- Active Waiting
- New Maudsley Carer Skills Podcast Series
- Youtube videos on how to support
- Animations: Dad's story, sibling's story and ED Voice
- Conference and webinar recordings
- FBT & CBT-E explanations
- Speaking to your GP



Support  
Services:  
✓ Helpline  
✓ Email  
Support





# Training in Therapeutic Support and New Maudsley Carer Skills

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**BODYWHYS**  
The Eating Disorders Association of Ireland

# Who looks for training?

- 45 Training Requests in 2023
- HSE – acute hospitals, community health services, maternity hospitals, MH teams
- Voluntary organisations
- TUSLA – residential care homes, foster carers
- Allied health professionals e.g. dietitians
- JIGSAW

# Types of Training Workshops

- Foundation level short training ‘Understanding Eating Disorders’
- Training in Therapeutic Support ‘Working / Supporting People with Eating Disorders Therapeutically’
- New Maudsley Carer Skills Training – 3 day training.

# Co-Production

## Bodywhys & HSE NCP-ED

- Self care App
- Active Waiting Project
- SEED Working group
- eBe Group

# Expert By Experience Group

- The Patient and Carer Voice
- 49 members of the Bodywhys eBe group, comprising:
- 31 people with lived experience (5 males, 26 females)
- 18 carers (15 mothers and 3 fathers)
- The eBe group represents people with experience of all eating disorders (Anorexia, Bulimia, Binge Eating Disorder and ARFID) and of all illness duration and severity





# Social Awareness

- Media & Communications
  - All media
  - Podcasts
  - Research
  - Ebulletin
- Eating Disorders Awareness Week
- Working alongside other NGOs e.g. Mental Health Reform
- Working other voices for EDs
- Public Information talks and presentations

# Social Awareness

- Education – Primary school ('Happy to be Me')
  - Age appropriate material (2<sup>nd</sup> Class+)
  - 137 teachers
  - 6,646 pupils
- Post Primary school (#MoreThanASelfie programme)
- 'Be Body Positive' Flag initiative
- - Post Primary Schools
  - 360 teachers
  - 86,612 students
- Training for teachers/ Guidance Counsellors / TY/ SNAs



# BODYWHYS

The Eating Disorders Association of Ireland

Thank You!

# Zuzanna Gajowiec



- Certified Eating Disorder Specialist & Supervisor
- Clinical Psychologist
- Chair of the Irish Chapter of the International Association of Eating Disorder Professionals
- Family Therapist
- Co-founder of Supported Families



# Eating Disorders:

Complex neuro-bio-  
psycho-social disorders

Curable

Not choices!!!

Not caused by  
families!!!

Affect all genders,  
races, ethnicities, body  
shapes and weights,  
sexual orientations, and  
socioeconomic  
statuses.

Happen over the  
lifespan  
(Mid-life/Elderly)

Treatment should be  
person centred

# Why are eating disorders harder to treat?



- Disorders of denial
- Ambivalence persists (not only at the onset)
- Eating disorders thrive in isolation and disconnection.

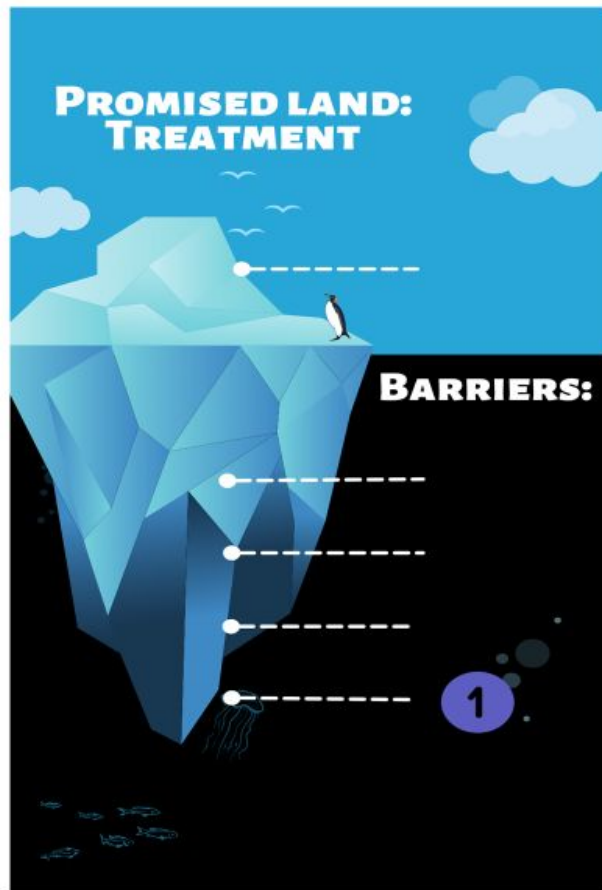
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One person dies as a direct  
result of their eating disorder  
every 52 min\*

\*Eating Disorders Coalition. (2016). Facts about Eating Disorders: What the Research Shows.  
[http://eatingdisorderscoalition.org.s2o8556.gridserver.com/couch/uploads/file/fact-sheet\\_2016.pdf](http://eatingdisorderscoalition.org.s2o8556.gridserver.com/couch/uploads/file/fact-sheet_2016.pdf)

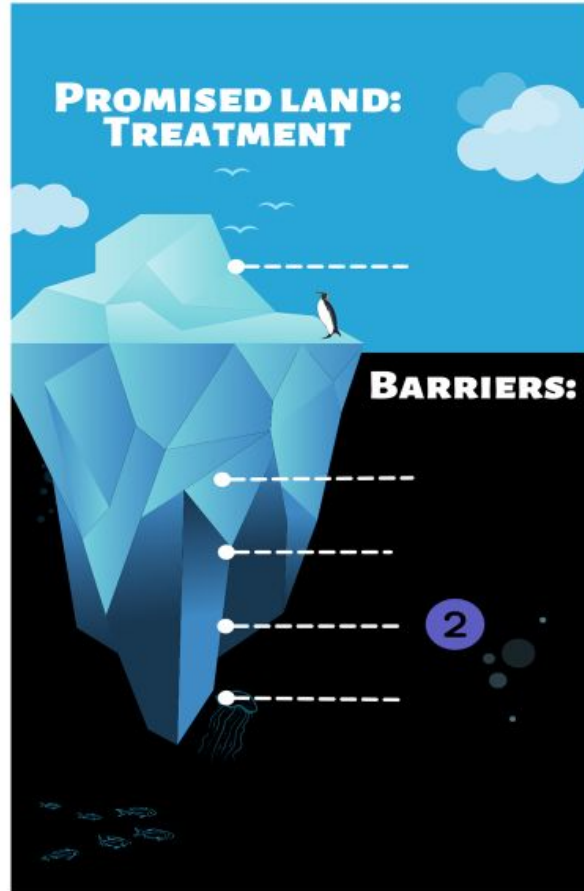


## 1: Natural Delays:

Researchers\* compared time between first symptoms (as reported by parents) and diagnosis to time between deviation in the weight growth curve and diagnosis:

growth curve showed change **9.4 months** prior to first reported symptom

\*Marion M, Lacroix S, Caquard M et al. Earlier diagnosis in anorexia nervosa: better watch growth charts! J Eat Disord. 2020; 8:42. DOI: 10.1186/s40337-020-00321-4



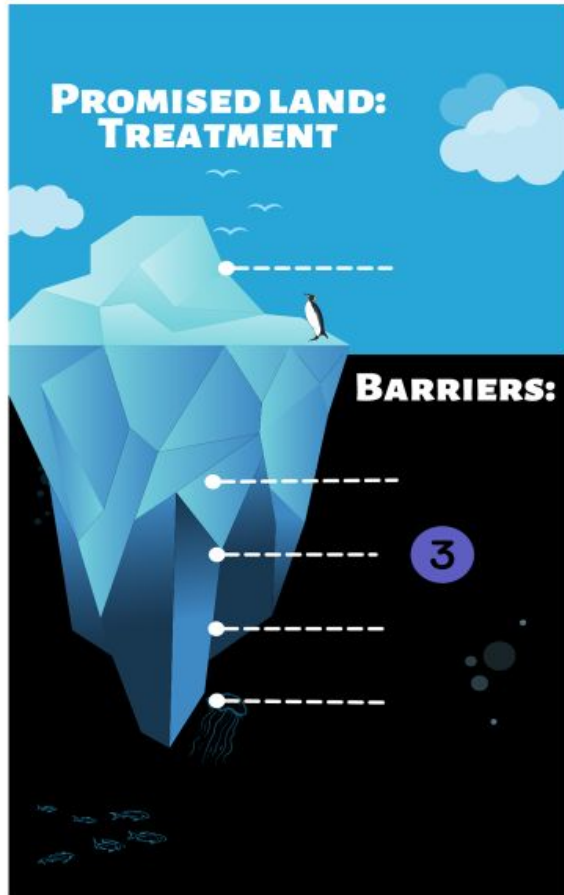
## 2: First Responders:

First Responders:

- GP's
- Therapists
- Dietitians
- Teachers/Sports Coaches etc

Importance of Specialized eating disorder training for GP's

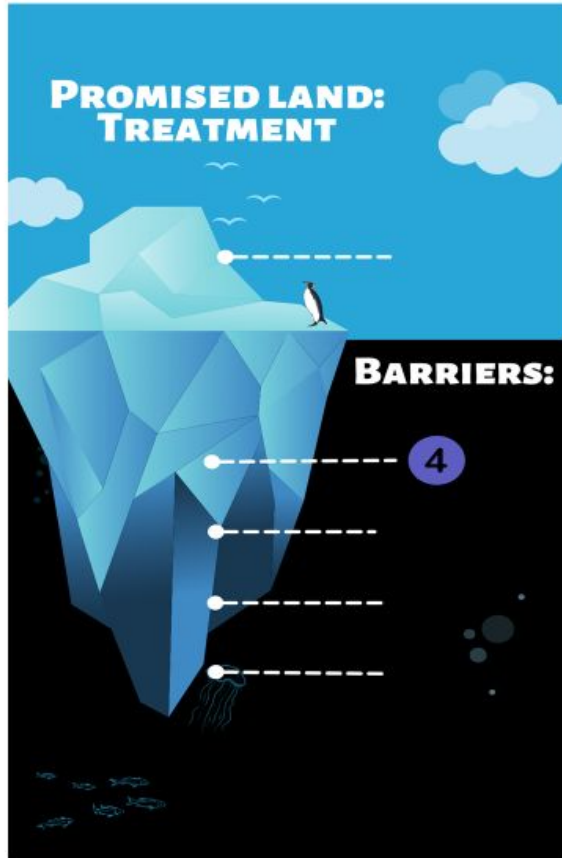
Most GPs receive limited to no training  
(at best only 2 hours training)



### 3: Removing the BMI barrier:

- Only **6%** of people with eating disorders **are underweight\***
- People with “normal and higher” BMI can’t access care
- BMI 12.5 to access hospitalization, regardless of how unwell the person is (despite MEED guidelines)

\*Weight Status and DSM-5 Diagnoses of Eating Disorders in Adolescents From the Community; Martine F Flament, Katherine Henderson , Annick Buchholz 3, Nicole Obeid, Hien N T Nguyen, Meagan Birmingham, Gary Goldfield



## 4: Eliminating delays

Delays lead to :

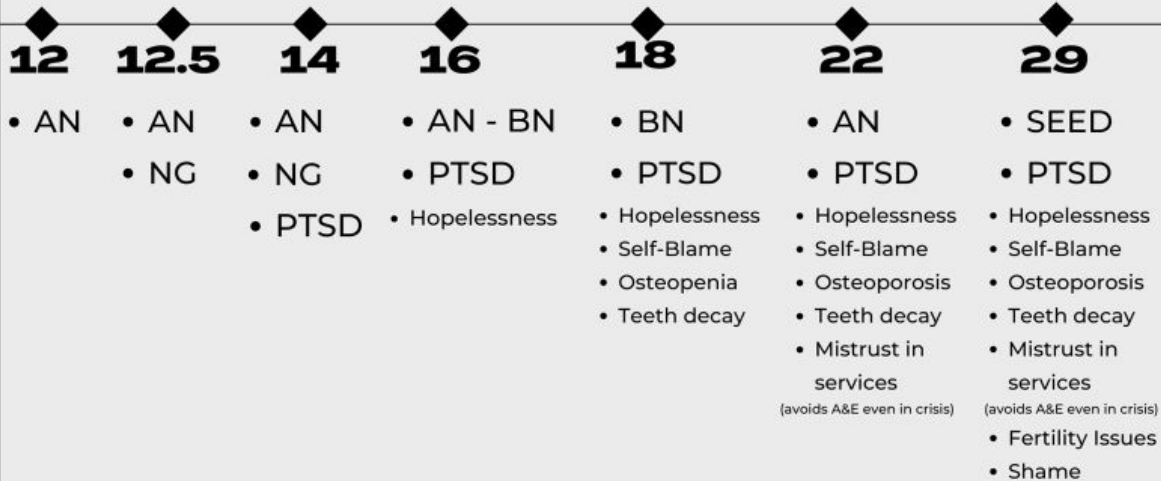
- Rapid deterioration
- Co-morbid issues
- Highest mortality rate of all mental health disorders
- Untreated eating disorders **can set in motion a cascade of complications**, magnifying the severity and chronicity of these conditions.

### Importance of Early Intervention\*

National Eating Disorder Association. Why Early Intervention for Eating Disorders is Essential. Retrieved from <https://www.nationaleatingdisorders.org/blog/why-early-intervention-eating-disorders-essential> on Sept 30, 2019.

# The cost of treatment delays:

## TIMELINE





## 5: Promised Land: Treatment

- Limited access
- Lacks services: Day program & Day Hospital level of care
- Lack of coordination
- No awareness and integrated treatment pathways for neurodiverse populations/ LGBTQ+, awareness of different issues and specific presentations in other marginalized communities.
- **Treatment transitions - risk of relapse**



## Most important things to optimize care:

Working with  
qualified  
professionals

Early  
intervention



# We can do better

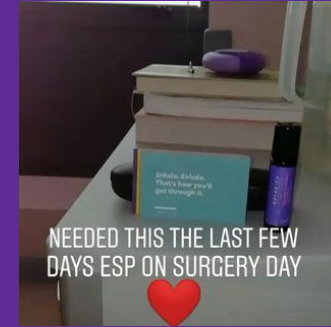
## We can save lives

# Ciara

This is little  
ciara...where  
did it all go  
wrong?



The beauty of life is,  
while we can't undo  
what is done, we can  
see it, understand it,  
learn from it and  
Change.



**This little girl was girl full of hopes and love, little did she know that she would spend most her life struggle with a life treating illness**





Eating disorders do not have  
a look!!!!

You can not tell by looking at  
somebody!!!!!!

In both these pictures i was  
quite unwell with an Eating  
disorder





I was told I had a long chronic enduring eating disorder and that i would never get better ... i received my last rights twice and said goodbyes to family.

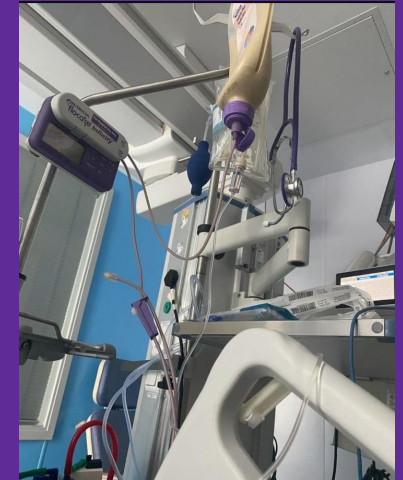
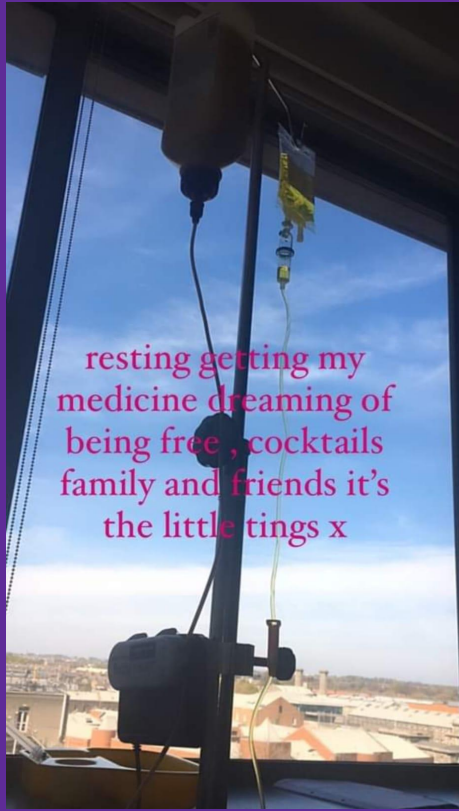
I received no hope ..We need encouragement, support and empathy and understanding.we need to be listened to and to feel safe.

Behind the diagnosis is people's story an individual, love ones also effects by this illness

State not Weight ... weighing scales tells us nothing about our mental health. I was sick at 5 stone and now at my stable weight.

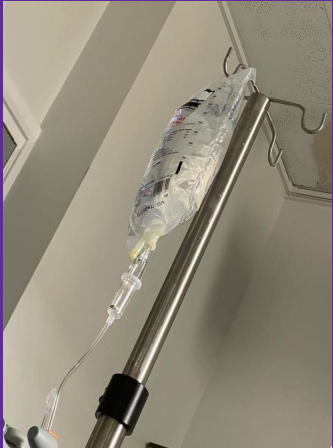


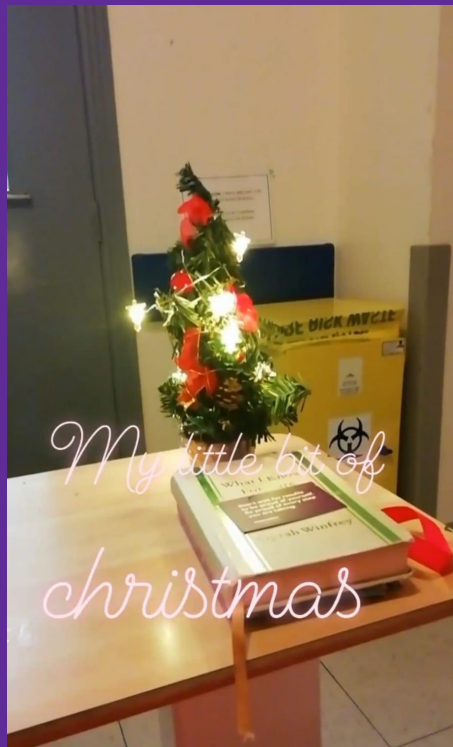
Drips, ambulance trips and icu  
monitors became a very  
normal part of my life





This was me on  
new years eve 2  
years ago in icu  
Literally fighting for  
my life. My body  
was tired





Eating disorders do not go away on holidays.

I have spent some lonely christmas in hospital.





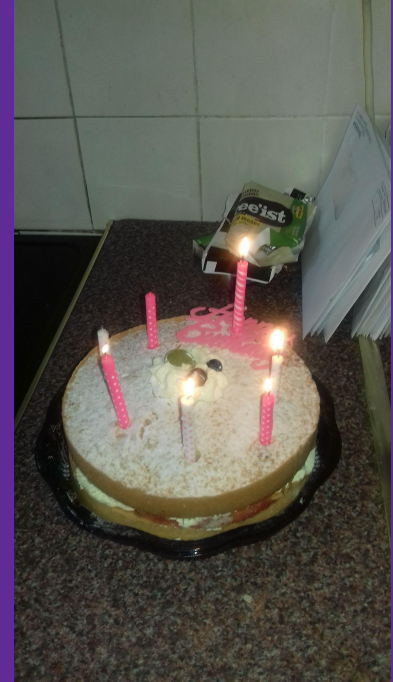
This is the hospital chapel , in my dark days i would be wheeled down in my wheelchair praying for peace in my mind. There were many times i just thought dying would be easier.

My family and friends saw me deteriorating before their eyes, I survived a heart attack, being in a coma, embolism rupture and many other complications. I'm still here.

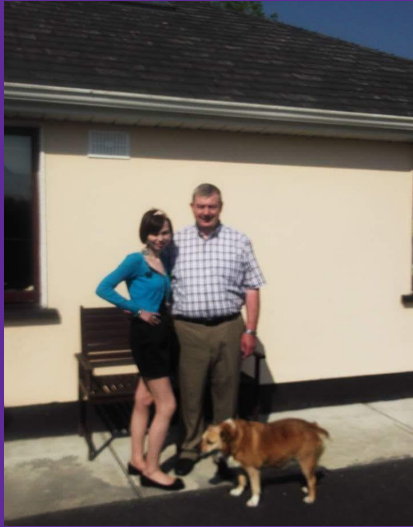
# Birthdays Robbed

- ❖ My **15th** birthday in an adults psychiatric hospital on nasogastric tube..no cake.
- ❖ My **16th** birthday
- ❖ **18th** and **19th** birthday
- ❖ My **20th** birthday
- ❖ I spent my **21st** in my first residential private treatment center
- ❖ My **22nd** birthday my **24th** birthday
- ❖ My **27th** birthday in residential treatment again.
- ❖ My **29th** birthday
- ❖ My **30th** was spent getting my hip replacement due to severe osteoporosis
- ❖ My **31st** birthday

I will never get these moments back. In a few weeks i will turn **35** and i will be celebrating with my friends and family i never take these times back.



# Family

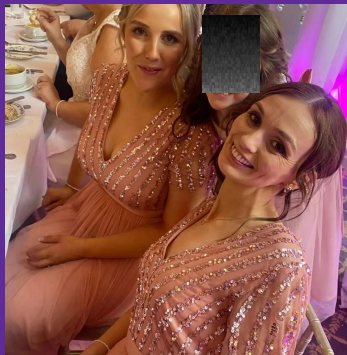
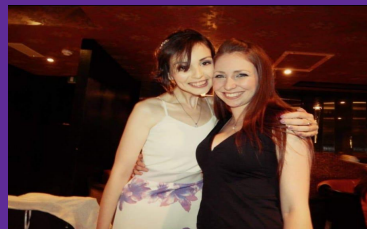


This illness has affected the whole family..some of my relationships will never be the same.

I may be the one with the illness but I needed this illness to cope with other issues within my family. This is why only treating the person with the illness with food won't help heal the person.



what doesn't kill you  
makes you stronger



## Recovery

Realizing that you're worth it.

Experiencing true happiness.

Caring about yourself.

Overcoming your demons.

Validating your self worth.

Exciting new world.

Realistic expectations.

Yearning to live.





I no longer live on  
Nutritional supplements. I  
still struggle with food  
thoughts but i now can see  
food is about so much more  
connection, comfort, being  
social. But it's taken daily  
support for my cci coach  
that's gotten me in a better  
place. This support is vital.



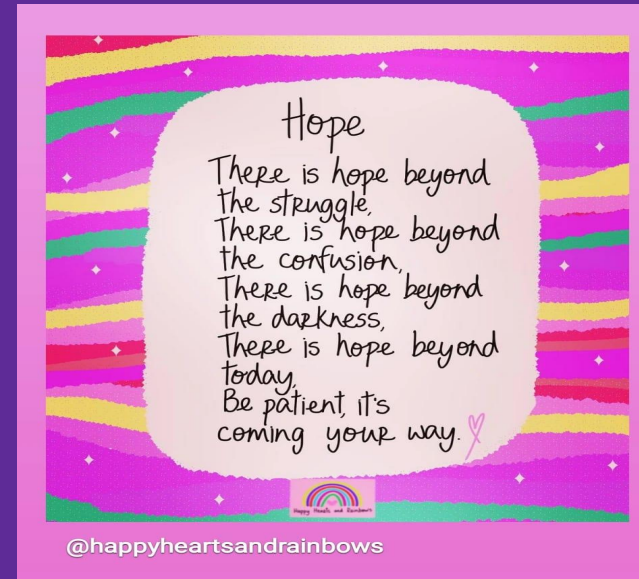




I can't stress how important your support network is. I have amazing 4 friends who have been rocks and keep me going on the bad days . Yes you lose a lot of relationships being unwell but you also Learn who really matters. Thank you Emily, Claire Ailish and Becky



Even on my darkest I held on to hope.  
Knowing there would be a reason I went through this.





Six years ago my greatest  
reason to recover was  
becoming an auntie.

Saoirse and Mya only ever  
saw me as auntie cici  
They truly love me for me.  
They taught me to love ice  
cream just because...  
And so much more.

Saoirse is 6 years old she  
is my godchild her name is  
irish for freedom and i truly  
feel she gave me that gift..



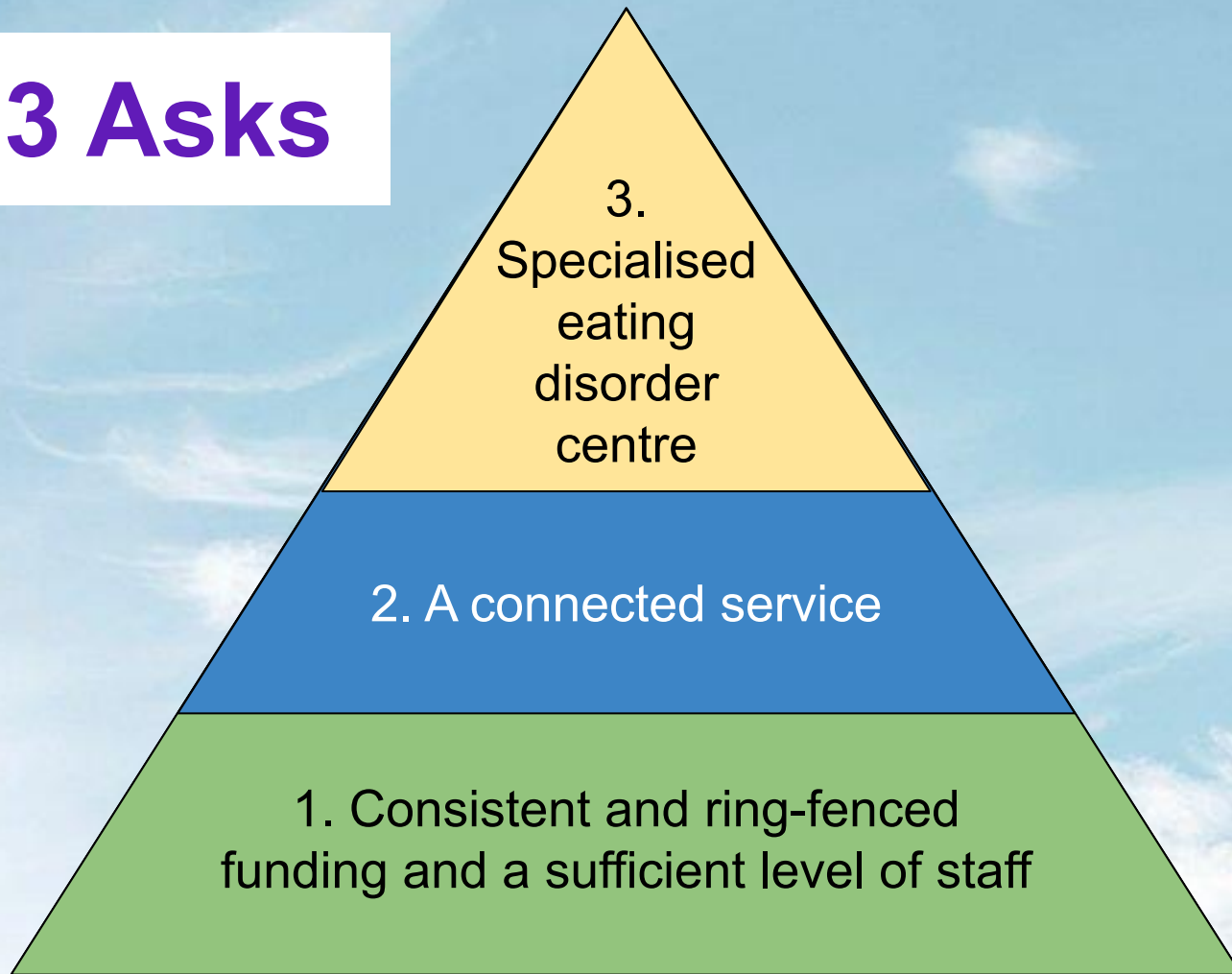


*What do you see in a  
recovery..someone eyes  
..my eyes are alive again.*

*Weight is one part of the  
illness but i can now  
smile and really mean it.*

**State Not Weight.**

# Top 3 Asks





# 1. Consistent and ring-fenced funding

Consistent funding is needed every year to maintain services, let alone improve services, so providers know what funding they can rely on each year.

Funding is needed to:

- Update the expired 2018 Eating Disorder Services Model of Care.
- Hire and train more staff.
- Address recruitment and retention issues.
- Provide a sufficient level of outpatient services.
- Expand specialist eating disorder teams.



# Sufficient level of staff



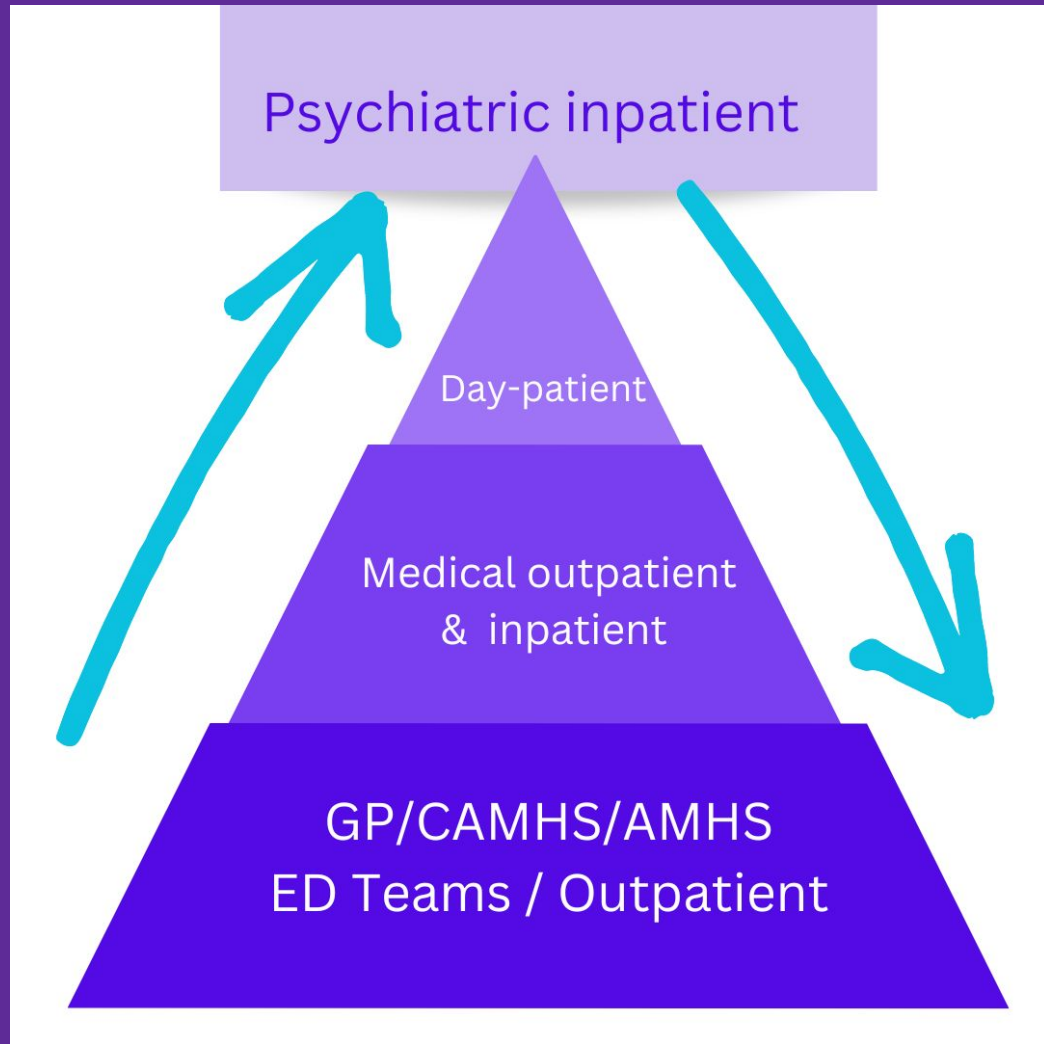
Staffing issues are a huge disservice to care, leading to incomplete teams, staff stress and burnout, closure of beds, and long waitlists.

Staff are needed to:

- Reduce CAMHS waitlists.
- Complete outpatient teams and specialist eating disorder teams.
- Reopen beds in CAMHS facilities and open additional specialised hospital beds.



## Stepped Model of Care



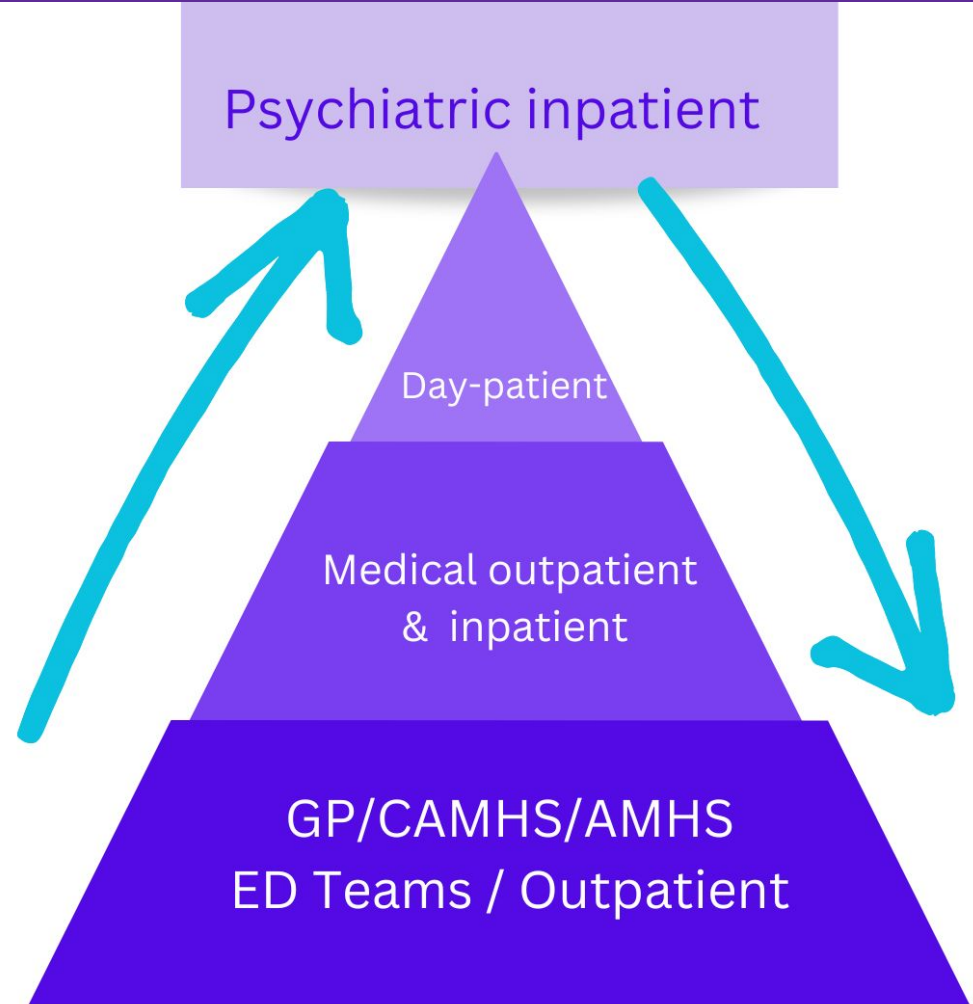
# Practical examples

## Top Levels:

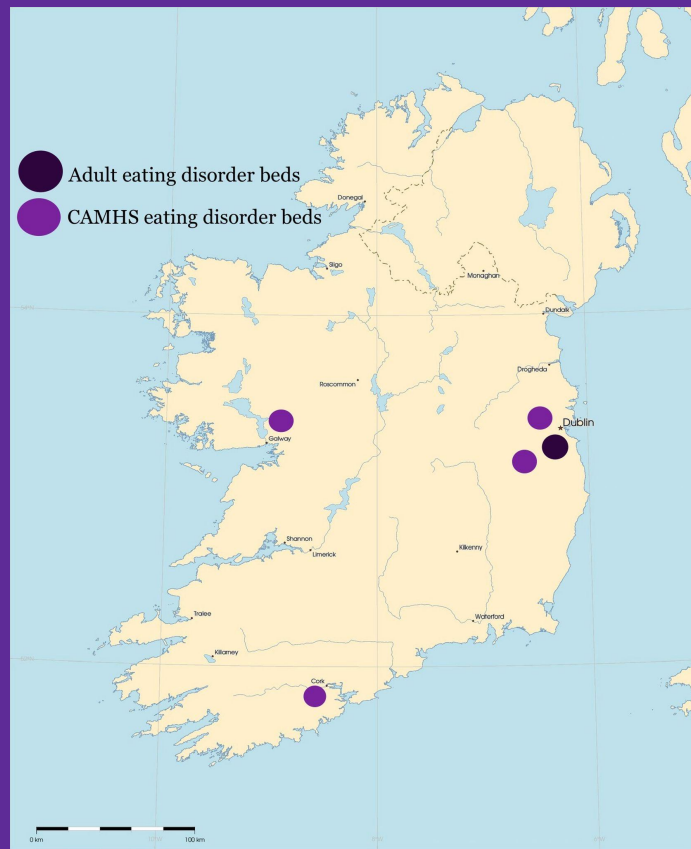
- Active involvement of a keyworker.
- Therapy.
- Meal support.
- Recourse/advocacy services for families.
- Clear communication regarding treatment plan.

## Bottom Levels:

- Assignment of keyworker.
- Care plan created.
- Early interventions, information, and supports provided for sufferer and parents.
- Meal supports and coaching.
- Therapy.
- Same level of treatment across all CAMHS facilities (NG).
- Pathway for people who are neurodivergent.



# Specialised Eating Disorder Centre



Knowledgeable staff with specialised training.

Physical and mental health treatment can co-occur.

No catchment restrictions.

Better use of funding than a disjointed, disconnected service.

Better chance of recovery with consistent care; not constantly changing teams or hospital environments.

# In Remembrance

Cathy



“The beautiful butterfly,  
flying high, unaware of its  
beauty, unsure of its  
wings.” -Poem by Cathy

Michelle

Michelle’s photograph is not  
here, because she placed more  
emphasis on what is on the  
inside, not the outside.

# Questions?



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