

EATING DISORDER SERVICES

‘We sent my daughter to the UK to save her life’

The HSE incurs more costs by not intervening early in eating disorder treatment. But the true cost is borne by the families affected



WEEK TWO

As revealed in the first of our two-part series on eating disorders, there has been a steady increase in the demand for services nationwide; one which far exceeds capacity.

Research consistently proves that early intervention is key for treating these disorders, but in Ireland, a lack of community-based services and long waiting lists means that child and adult patients often end up in inpatient psychiatric beds, where they do not receive specialist treatment.

Psychiatric beds are intended as last resort options, but, for the first time, eating disorders were the main reason for children's admission to psychiatric care in 2023. Figures from the Health Research Board revealed that under-18s presenting with eating disorders comprised 24% of emergency admissions to psychiatric units and hospitals.

A failure to assess and treat patients with eating disorders in a timely manner is not only affecting their recovery but also driving up costs, with the HSE sending patients to the UK for treatment under the Treatment Abroad Scheme (TAS).

This scheme covers the cost of planned treatment for Irish healthcare patients in the EU, UK and Switzerland.

In other cases, treatment abroad for

eating disorders is funded directly through local mental health services rather than TAS, according to the 2018 Model of Care document, which includes a five-year plan to improve eating disorder services.

View of parents

Irish Country Living spoke to three parents whose children have been treated in the UK.

Carers are often hesitant to pursue treatment abroad for family members with eating disorders, due to fears about the impact of sending a patient, who is already vulnerable, to a foreign country where they do not have access to their support system. However, sometimes there is no other option.

Mairead's* daughter Sasha* has spent the last six years in a specialist eating disorder hospital in the UK because there is no bed for her in Ireland. "Sasha left her home in Co Limerick seven years ago to be treated in A&E and has not seen her bedroom since," says Mairead.

Mairead describes "a total lack of knowledge" when it came to her daughter's diagnosis. "We brought Sasha (then 15) to the GP when she was restricting food. They did heart tests but never mentioned that it could be an eating disorder. We had about three years of this back and forth."

At 17, Sasha ended up in Merlin Park University Hospital in Galway, where she was the first person to be NG fed [nasogastric feeding is a feeding tube inserted in the nose or mouth to deliver nutrition directly to the patient]. Sasha stayed there for 10 months until she turned 18.

"[At that stage], she was eating orally and was a healthy weight.



Carers are often hesitant to pursue treatment abroad for family members with eating disorders. istock

Then all of a sudden there was a talk about discharge and we were like, 'what does discharge look like?' We were told: 'there is nothing [in terms of services] as an adult'."

Sasha was discharged, not because she was ready, but because she was an adult. Without support, she stopped eating again within four weeks. Mairead was told to bring her daughter into A&E if she went three days without food or water. That's exactly what happened.

Sasha was brought into a local psychiatric ward, with no specialist eating disorder beds or team. "It was not the proper place for a vulnerable 18-year-old to be. She was there for about two months

and we got a private appointment with St Patrick's Mental Health Services," says Mairead. "They don't have NG feeding, so she lost so much weight that she ended up in resuscitation in St James's Hospital in Dublin."

As Sasha would not eat, she had to be made a ward of court [where the High Court has legal responsibility for her welfare] so the hospital could NG feed her. She has been a ward of court ever since and is 24 years old. "We had to witness men in white coats in St James's sedating Sasha

‘We sent her to the UK to save her life because there was nothing here in Ireland’

and holding her down and her screaming. "We were told that she needed specialist treatment to keep her alive and the only place is in the UK," says Mairead.

The true cost of an eating disorder is borne, not by the HSE, but by families and patients themselves. The impact includes disruption to education or employment, as well as significant family stress. Several parents described it as "walking through hell." Sasha was transferred by air ambulance to the UK in 2019 where she continues to receive treatment.

Treatment Abroad

Following a request for information, the HSE provided *Irish Country Living* with figures on the Treatment Abroad Scheme, including the total cost and number of patients.

Year	Approved patients	Cost
2024	-	€4,923,633
2023	-	€4,687,978
2022	-	€3,187,475
2021	-	€321,959
2020	-	€977,078
2019	-	€804,352
2018	-	€176,131
Total	20	€15,078,586

*The HSE cannot provide the number of patients per year as the number is five or fewer per year.

The table (above) shows the TAS spend from 2018 to 2024. Although a breakdown of patients per year was not provided, it totalled 20 people over seven years. The overall spend during this time was just over €15m. When this is broken down, it equates to €753,929 per patient.

The question has to be asked, should the Government not have invested this money into providing badly needed community services rather than sending vulnerable patients abroad for treatment? Furthermore, as mentioned, there is funding for treatment abroad through local mental health services. This is outside the TAS funding.

This operates on a case-by-case basis and the HSE could not provide recent records to *Irish Country Living*. This is additional spend to the aforementioned €15m.

‘Sasha left her home in Co Limerick seven years ago to be treated in A&E and has not seen her bedroom since’

Failure to intervene early in eating disorder treatment is creating a false economy in Ireland with the State incurring more costs by purchasing private inpatient beds abroad. These are then used as substitutes for community eating disorder services in Ireland, which are under-resourced and under-staffed.

What the figures fail to capture is also the emotional and health impact of delayed intervention on patients and their families.

This is the public expenditure but what about the costs that families face? There is some basic funding under TAS for families.

When Sasha was initially sent to the UK, she was funded under TAS. This covered her treatment in a private hospital and certain elements of the family's travel to visit her [flights, not including luggage or accommodation].

After the first three months of visits, Mairead and her family were finding it difficult to get reimbursed. The judge presid-

ing over the case at the time [High Court President Peter Kelly, now retired] ordered the HSE to fund all visits to Sasha and they have been funded under that arrangement with the HSE since 2018.

To understand the out-of-pocket costs faced by families on treatment at home and abroad, *Irish Country Living* conducted a survey with Cared Ireland, a voluntary group comprised of families who have been affected by eating disorders. The survey received 67 responses from those with eating disorders or their family members.

The results showed that out-of-pocket expenses for eating disorder treatment were commonly reported to be between €5,000 and €20,000, with 20% of those surveyed spending between €5,000-€10,000. Some carers have spent over €100,000. These expenses include private consultations with GPs, dietitians, therapists, and in some cases, hospital admissions.

Another big cost is carers giving up or cutting back on work to look after their loved one. Mairead had to go part-time in work to look after her daughter. A significant number of carers reported leaving work permanently (21%) or temporarily (34%) or shifting to part-time work to provide full-time care (19%).

The indirect costs – such as lost income, travel, and emotional burnout – were frequently cited and often exceeded direct medical costs. When asked to estimate the costs of giving up or cutting back on work, 24% estimated the cost to be between €15,000-€30,000.

"Ireland's system is not adequately supporting eating disorder patients or their carers," Cared Ireland says. "Timely diagnosis, equitable access to care, and financial and workplace support are lacking. Carers are often left to bridge these gaps alone – financially, emotionally, and professionally."

The emotional toll

To get a full picture of eating disorder services in Ireland, and the impact on patients and their carers, *Irish Country Living* spoke directly to 11 families and surveyed 67 people as part of this series. The strain on families is evident.

Mairead is deeply upset at comments made by Mary Butler, Minister of State at the Department of Health with special responsibility for mental health when she spoke on the issue in the Dáil in March.

"Many people choose to use the treatment abroad scheme themselves. They actually choose to use it," said Minister Butler.

SUPPORT SERVICES

➤ If you or someone you know is affected by an eating disorder, support is available from the following:

➤ BodyWhys is the national voluntary organisation supporting people affected by eating disorders. Their helpline is 01-2107906 and they also run free online support groups for people with eating disorders, as well as for their families. bodywhys.ie

➤ Cared Ireland is a voluntary group comprised of families and carers affected by eating disorders. They advocate for an improvement in eating disorder services in Ireland. caredireland.ie

➤ Mind EveryBody is an advocacy group who want to see reform in eating disorder services in Ireland. They aim to raise awareness and promote better understanding on eating disorders. mindeverybody.com

➤ The College of Psychiatric of Ireland is a partner of the National Clinical Programme for Eating Disorders and offers public information on eating disorders. irishpsychiatry.ie

"The Minister's comment upset us so much as a family," says Mairead. "If there was any way of our daughter staying in Ireland, she would have wanted to stay around her family and friends. We sent her to the UK to save her life because there was nothing here in Ireland. I truly believe had she been treated in Ireland, she would have had a better chance of recovery."

"I suppose as parents we constantly think every day: what if?" says Mairead. "What if our GP had been able to diagnose our daughter's eating disorder at the age of 15? What if the adult services team in Limerick had someone trained in dealing with eating disorders? What if our daughter hadn't needed to go to the UK for a specialist bed?"

"Each one of these 'what ifs' is a failing by the Government and HSE. We could be in an entirely different situation if even one of those 'what ifs' was a reality."

Mairead's 'what ifs' are more than unanswered questions: they make clear there is a human cost to a lack of eating disorder services. Lives lost, lives in limbo.

This raises a question for Minister Butler: What if nothing changes?

*Names have been changed to protect the privacy of individuals.

WORDS OF LIFE

For there is one God, and one mediator between God and men, the man Christ Jesus, who gave himself a ransom for all.

I Timothy ch. 2 5 & 6