NEWS

Hospital unit unaware how many seriously ill 'orphans' in its system

Vulnerable patients at Children's Health Ireland were denied critical care and transitions to adult services, their families tell *John Mooney*

"I could have lived a more independent life but that's been taken from me," said Lena. "If I had received the treatment I needed, I could have lived alone and taken care of myself. Now I face a life of living with my parents as I rely on them to care for me."

Lena is a pseudonym given to one of the patients at the centre of the latest scandal at Children's Health Ireland (CHI).

Her mother, Anne, who cannot be identified, paints a bleak picture of the care provided at the CHI department. She spent years trying to secure services for her daughter until she reached the age of 16 when she was officially discharged.

"CHI did not transition these children into the adult healthcare system. She was discharged when we turned up for an appointment," she told The Sunday Times.

The consequences of this became apparent a week later when Lena developed a significant health issue.

"When we rang the hospital and asked if we could come in, they said, 'No, you're discharged. Go to your local hospital.'"

At the time, Lena was vomiting. She couldn't keep food down. She had chronic headaches. Her mother said she was going toxic. Anne lodged a succession of complaints to the CHI hospital but no one listened.

"My complaints went nowhere. They always came back to the same thing, even though my daughter had been dumped out in the middle of a healthcare crisis. If you make a complaint about CHI, you become the problem. And if you blot your copybook, you know, you're not looked after again. I am not surprised at what's coming out now," she said.

"We knew all along these children were being aged out of the system, allowed to enter adulthood so the problem moved elsewhere, but we could never prove it. At the time, I lodged a massive complaint but got nowhere. I was so upset for her."

Lena is among a cohort of child patients, who were referred to as orphans in the hospital system, born with a serious condition who depended on hospital care to live to their full potential.

Some orphans could walk but others were confined to wheelchairs, grappling with profound physical and personal challenges that often left them in undignified pain.

At CHI they were meant to be safe and provided with treatment. But, for some, the care they needed never materialised.

As a consequence, many were denied the opportunity to have procedures and access to treatments that would have allowed them to develop the skills to grow into independent young adults – a future that both they and their families hoped was within reach.

Now, amid a deepening scandal first exposed by The Sunday Times, the reality of what happened to them and other child patients at the CHI hospital is coming to light.

Rather than avail of first-class medical care, they found themselves stranded at the CHI hospital department that is now the subject of multiple investigations, unable to access services.

The treatment of the orphans was raised during the 2021 internal investigation into a CHI hospital, which uncovered a catalogue of other dysfunctions, among them a consultant who devised a scheme to enrich himself at the public's expense; surgical trainees being subjected to humiliation; and children subjected to intolerable risks because of mismanaged services.

The internal investigation itself was unknown to the public until The Sunday Times last week published its findings, prompting multiple investigations and an internal audit by the HSE to establish if there were more cases of sharp financial practices by consultants.

At the time of the 2021 investigation, responsibility for providing care to the orphans should have been transferred to another CHI-run hospital, but the children and adolescents were left behind due to their specific needs.

Hence they became known within the CHI hospital system as the orphans, a name also used by the 2021 internal inquiry.

Why this happened remains unclear – the 2021 investigation team could not determine the root cause.

But the consequences were stark: children were denied access to critical services, in breach of established best practice as the inquiry concluded. Astonishingly, the hospital department did not even know how many of these so-called orphans were in their care – or that some existed at all.

Was it 12 patients, 18 patients or 80 patients? No one knew. The hospital gave different figures to the internal investigation. An internal effort to determine just how many orphans were in the system led nowhere. Investigators ultimately concluded that these children had been left in limbo – unable to access services in line with best clinical practice.

For those affected, the consequences could hardly be more serious.

Last week, The Sunday Times spoke to some of the orphans and their families at the centre of this affair – all of whom say they spent years trying, and failing, to hold CHI and its management to account.

For legal reasons, neither the individuals nor the specific condition they suffer from can be named, but their families, whose names have also been changed, have come forward to reveal what happened to them.

Because they were denied the care and treatment they needed as children, some of them will face more difficult futures. Some will have to spend their adult lives living with their parents who care for them while others will fight to overcome their life-threatening conditions.

The treatment of patients like Lena was repeatedly raised by staff at CHI to the 2021 internal investigation team. Almost a third of the hospital staff they interviewed on condition they would never be named or quoted in any report said the care provided to the teenagers was not in line with best practice.

The inquiry itself found the orphans could not get appointments with a consultant. For reasons unknown, the orphans were never placed under the care of a specialist consultant based at the hospital department under investigation. The parents say they relied on doctors who had an interest in the area.

What has emerged most starkly in recent weeks is a troubling absence of accountability within CHI. The organisation has shown itself to be either unwilling or unable to take responsibility for serious lapses in care.

As the 2021 investigation found, internal complaints by staff were often met with silence or deflection. Concerns were also routinely dismissed or delayed in bureaucratic limbo. Staff were bullied, forced to resign and became depressed working in what was a mismanaged, toxic environment.

To make matters worse, concerns about the treatment of child patients who suffer from this specific condition were uncovered in 2017 when they were the subject of a previous inquiry by an external team. That inquiry concluded that such patients had not received anything close to the standard of care expected in a modern health system.

Four years later, the 2021 investigation struggled to identify what, if any, action had been taken by CHI in response to the earlier report that examined the services on offer.

In the meantime, some of the children had effectively "timed out" of the paediatric system: they had become adults and transferred to adult services, often without appropriate continuity of care, but solving the issue for CHI.

The 2021 inquiry yet again warned of exactly this scenario, highlighting the risks of inaction despite evidence that young patients who are taught to manage their condition and receive the procedures they need can avoid severe deterioration.

"When I read last week's story I knew my child was one of the orphans discussed in the report," said Rose, the name used by another parent.

Like other mothers interviewed, Rose spent years demanding the hospital department in question provide proper care to her son.

"You were fighting, fighting, fighting all the time to try and get him into a system that didn't really exist. I developed a relationship with a nurse. She would ring and say, there's an out-of-minute cancellation. Can you make it in the next two hours? I missed my grandmother's funeral to make one," she said.

"CHI knew our children were receiving substandard and suboptimal care as I wrote to them so many times, but they did nothing," she added.

Each parent of the orphans interviewed for this investigation told a variation of the same story.

"Our boy was born in 2008. He was only six months old when he was assigned to the CHI department at the centre of this affair," said Marie, another mother whose son was among the cohort of patients whose care was investigated by the internal inquiry.

"They promised to move him to the specialist facility but never did. So we had some services and no services. They refused to transfer us to the specialist facility saying it was full. So we were left to linger," she said.

Marie has no doubt her son has been adversely impacted by the treatment he received from CHI.

"It's hard to be 17 years old. He was recently transferred to another CHI hospital, where he met a specialist. He was just beside himself with how awful the situation was. When you are 17 years old and living with a disability, you start to realise the things that are not really as they should be.

"It's a very, very tricky time for a young person. He's now being lined up for surgery that he should have had at ten months old. He's petrified and he doesn't really want to do it," she said. "I can't help thinking back to when I had my new baby all those years ago. I put all my faith and trust in the system. And then bit by bit, I began to realise, actually, this is a façade. I am the only one who is going to fight, totally ill equipped and totally terrified."

CHI is still refusing to answer specific questions about the actions it took following receipt of its 2021 internal investigation to help the patient cohort known as the orphans.

A spokesman said last week that "all appropriate action was taken" regarding the report. He said that "strong, collaborative leadership and consistent good governance" were the foundation of running an effective, efficient and best in class service across CHI.

"A number of underlying concerns, service gaps and issues were identified in a CHI service, which needed to be explored and understood in greater detail, to ensure supportive action and corrective measures could be put in place where required," he said. "This internal review report was presented to and discussed at the board. The recommendations were accepted, implemented and continue to be implemented. All appropriate action was taken."

The names of all patients and parents have been changed to protect their identity

> They were unable to access services

> Now I face a life of living with my parents

> The 2021 inquiry warned of this scenario

> I am the only one who is going to fight this

Father of soldier killed in Lebanon says allowance cut has left him 'poor'

Jennifer Bray Political Editor

The father of a soldier who was killed on duty in Lebanon has said he has been left "poor" after a special allowance that was being paid to his family was discontinued.

Michael McNeela was 21 when he was shot while serving on his second tour of duty in southern Lebanon in 1989.

A number of months after his death, his mother Kathleen was given a dependant's allowance under the Army Pensions Act, which the family continued to receive until her own death last year.

John McNeela, his 84-year-old father, has been told by Simon Harris, the minister for defence, that there is no provision in the Army Pensions Act for the monthly sum of €342 to be transferred to him, a situation that he says has left him in financial peril.

"I do feel let down by the government. My son gave his life for the country," McNeela said.

Michael was the 26th Irish soldier to be killed while serving with Unifil in Lebanon. A total of 88 Defence Forces personnel have lost their lives while on peacekeeping duties overseas in various missions.

Speaking about his son's death, NcNeela said Michael was "in the wrong place at the wrong time".

"He was killed on my birthday on the 24th of February 1989. A priest came down from the barracks to bring us the news. Life was never the same afterwards.

"He was on night duty. When he was being relieved in the morning, around 8.30am, he was making a cup of tea for the person who was taking over from him. A ricochet bullet was fired over the border and it hit him in the chest. He was in the wrong place at the wrong time," he said.

"He was killed at 8.38am in the morning. Some things stay in your mind. We didn't get him back for six days. He had to be brought from Tel Aviv to London. Then he was flown from London to Dublin airport. It was nearly a week before we got him home."

McNeela said his son had wanted to join the army since he was a boy. "When he was going to school, he would be writing to the army. He wanted to join and that was it. He wanted to be a ranger, that's what was in his mind. He joined around 1985 and was very well liked.

John McNeela's son Michael, 21, was killed on his second tour of duty in 1989

"He had done two tours of duty in the Lebanon when he was killed."

McNeela, who has three adult daughters, said that although his family had to find a way to go on after Michael's death, it had a huge impact, including on his wife, Kathleen. She suffered a brain hemorrhage last year and died unexpectedly.

A number of months later, an official from the Department of Defence contacted McNeela and told him the sum being paid under the Army Pensions Act could not be transferred to him. McNeela says this has left him in an extremely difficult financial position, and he has called on the government to amend the legislation if necessary.

"I don't know how long I have left to live. I worked on buildings all my life and I never paid into a private pension, so I have the contributory state pension, and I have to pay everything from this," he said.

"Not having access to this allowance is leaving me poor. It is only a pittance to the army or the government, what I would be getting. And after all, he was my son too."

He said there were long nights over the winter as he tried to keep the house warm and that he needed the use of a car because of some difficulties walking. He currently lives independently in Dundalk.

In a letter sent to the Sinn Fein TD Ruairí Ó Murchú about the case, Simon Harris, the minister for defence, said that there was "no provision" in the Army Pensions Act to transfer the payment to McNeela.

Harris said he was "sorry that the reply was not more favourable".

Under the Army Pensions Act, the father of a deceased person could only qualify for the dependant's payment if he was over 60 or incapacitated due to bad health. When the allowance was granted, he did not qualify under these terms.

The terms of the law allow the payment to be made to a deceased person's mother, however.

McNeela said he felt "let down by the state" and that he was appealing to the government to address the issue as it "would help me for only a certain length of time. I won't live to be 100. A change to this situation could also help other people."

Ó Murchú, the Sinn Fein TD for Louth, said: "It is not beyond the government to find an interim solution to this problem: in fact, it is the fair and reasonable thing to do here.

"For our part in Sinn Fein, we will be proposing our own legislation to address this issue. The government has moved before to resolve pension anomalies, and they should do so here too."