



REAL LIFE

“MY 23-YEAR OLD SON DIED WITHOUT WARNING

OF SUDDEN **CARDIAC** DEATH SYNDROME”

Dealing with the loss of a child in this way is harder than most. One mother speaks to *Woman's Way* about her loss *By Angharad Williams*

Most of us have been touched by a **cardiac** death in some way, whether it be a friend, family member or an acquaintance. Most tragic of all are the 60 to 80 **young** people under the age of 35 who die each year because of Sudden **Cardiac** Death Syndrome, the term used for causes of **cardiac** arrest in **young** people.

**Cardiac** disease in **young** people is mostly due to inherited heart disease or birth defects and in most cases the person is completely unaware of any problems they may have.

The charity **CRY (Cardiac Risk in The Young)** hopes to reduce the number of deaths by screening hearts of **young** people across Ireland and providing counselling and support to families affected by Sudden **Cardiac** Death Syndrome.

One woman who appreciates the work of **CRY** more than most is Jane Williams. Her son Hugh suddenly passed away in 2005 during a game of rugby and prior to that day gave no indication that he was in any way ill. “Hugh was the youngest of our three children and he was a real fun-loving person,” Jane explains.

“He was always good for a joke and he was a real individual. He was a great guy, into all kinds of sport and he always wanted to be an architect like his uncle, so he had done three years in a Scottish university studying architecture.

“I have so many memories of him. In all the pictures we have of him he’s doing something slightly outrageous like hanging off the rafters.”

Hugh was a healthy 23-year-old and enjoyed the same things as most men his age and there was no real sign that there was a problem with

his heart: “In the period leading up to his death he lived at home with us for a year. He came back after travelling and we enjoyed that time with us.

“We had our house empty and suddenly it was full of him and his interests. In the year preceding his death there had been one incident when he was in Dublin where he said he didn’t feel well and the room was spinning, but we didn’t think anything more about it. We found out after his death that while he was travelling Australia he had fainted for no reason, but it was put down to the heat. He told his friends he was fine and they continued travelling. Those were the only two things that happened which gave any sign that something could be wrong. He was slim, tall, **young** and energetic and he didn’t give us the slightest indication that there was a problem.”

All her three of Jane’s children are extremely sporty and Hugh had joined his brother’s tag rugby team and was soon a popular member of the team.

“On the day he died he’d been playing tag rugby with his brother. Hugh had only recently taken up the game, although he had played rugby at university, and two weeks before he died he’d actually scored the winning try and we have pictures from the day. Before he died he was called off to substitute for someone and he walked across to the sideline and asked his brother for a drink, took a sip and then just dropped to the ground. That was all that happened.

“They realised quickly that it was serious and people did give CPR to him but there was no defibrillator there. They called the ambulance but it took some time to get to him and it was clear when he was in the



Hugh with his teammates shortly before his death

“**Hugh was always good for a joke and was a real individual**”

ambulance that it was very serious. I was at an official dinner and my husband was at a family birthday party, I had my mobile off and it was very upsetting for my eldest son because he couldn’t contact us. It took an hour for him to manage to get hold of us. My son could hardly talk, but he said Hugh’s death was instant, that he dropped to the ground and didn’t wake again. We know now that unless you get the defibrillator in the first five minutes there isn’t much chance of survival. It might not have saved him, but it would have given him a chance.”

Hugh was pronounced dead at the hospital and in the following weeks the family were able to find some



sort of comfort in knowing what happened to their son.

"You're left with nothing but a bag of possessions," Jane said, "and that's shocking, but we didn't know quite what had happened. We were lucky he got a postmortem and we found out he had hypertrophic cardiomyopathy which is an enlargement of the muscle of the heart.

"But you don't get the results of the postmortem for some time and some people have to wait much longer than we did. In the meantime a programme appeared with Monica Martin who lost her son in 2005 and CRY was mentioned at the end of it. I sent them an email and they rang me back.

"When I came off the phone I said to my husband, 'That's the first person who's talked any sense since this happened.' You can talk to them because nobody else has a clue about how to talk to you and so CRY was really important because they understood what we were going through. They arranged for the whole family to be screened, which for me was a huge weight of my mind because my son wanted to get back to playing rugby and his friends.

"Even four years on it's still quite raw, it's extremely harrowing. I retired from my job at the Gowran Park Racecourse because I couldn't hack it at that time. All my colleagues were shocked about what happened and asked what would have made a

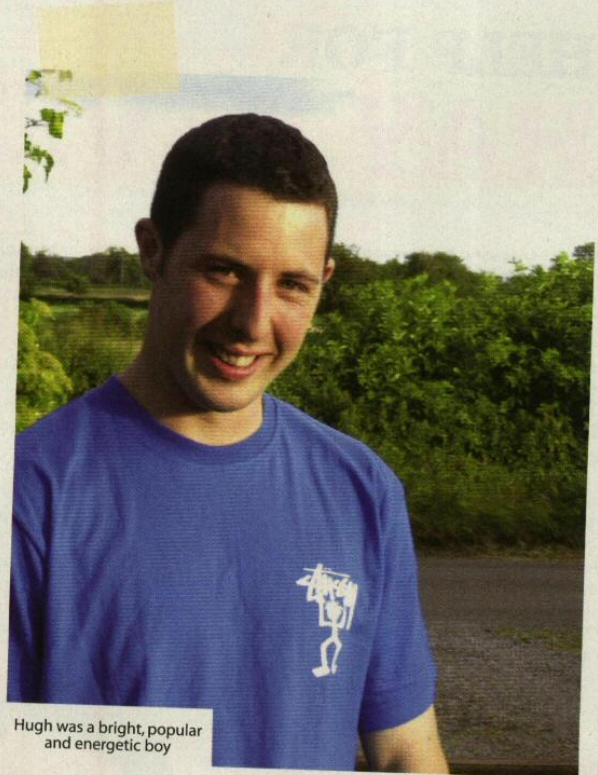
difference, so we raised money for a defibrillator for Gowran Park

"Now there is one on their hurling pitch, one in the village and one on the racecourse and golf course. We hope our story will make people recognise the symptoms and know that if someone drops like Hugh did, you don't bother to ask questions - you start CPR and get the defibrillator and you can give the first shock.

"It's so easy to use, the machine talks you through it. It's nothing to be scared of. Thankfully what happened to Hugh is rare, so there's no reason for alarm, but if you notice something unusual in your family then you should visit the GP. Since Hugh's death I've looked at my family history and found that my aunt died in a theatre in her early 40s.

"It's not like an ordinary death, it's so out of the blue and you obviously don't expect your children to die before you. I hope that because of his story he can help people, help people to get screened and get more defibrillators out there."

If you would like more information about CRY or Sudden Cardiac Death Syndrome contact 01 452 5482 or



Hugh was a bright, popular and energetic boy

*"It's not an ordinary death, it's so out of the blue and you don't expect your children to die before you"*

## COULD YOU OR YOUR FAMILY BE AT RISK?

The Centre for Cardiovascular Risk in Younger Persons, based in the Adelaide & Meath Hospital Tallaght, aims to provide a comprehensive evaluation of those diagnosed with or at risk from cardiovascular disease at a young age.

Cardiologist Dr Deirdre Ward outlines symptoms that may indicate underlying cardiac condition:

- Unexplained or unusual syncope (temporary loss of consciousness and posture)
- Significant unexplained dizziness
- Palpitations (if prolonged and if associated with dizziness or impaired consciousness)
- Disproportionate shortness of breath on exertion, especially if recurrent
- Chest pain on exertion, especially if it restricts ability to exercise

Other people who should get checked are those with a close relative who had a premature sudden death with suspected cardiac cause/unknown cause, for example:

- Cardiomyopathy - Hypertrophic (HCM or HOCM), Dilated (DCM) or Arrhythmogenic Right Ventricular Cardiomyopathy/Dysplasia (ARVC/D)
- Connective Tissue Disorders (eg Marfan's disease)
- Sudden death with normal heart on post-mortem
- Family history of one of above conditions even if death has not occurred
- Personal history of one of the conditions where advice on management was required

The Centre for Cardiovascular Risk in Younger Persons, which is based in the Adelaide & Meath Hospital Tallaght

