

# Why not?



Hope is a 15-year-old who lives with congenital heart disease. Her story is one of determination and girl power, but she believes she is no different to anyone else.

On the outside Hope appears to be fit and healthy, tall and athletic. On the inside, she has half a working heart. Debbie, Hope's mum, found out at 38 weeks that her baby had a heart problem and would need care at the Freeman Hospital. Her name was picked before the planned day for induction, Hope – because that's all they had at the time. When Hope was born it became quickly obvious to the medical team that she needed urgent care, so she was transferred to the SBCU for monitoring and medications. She was taken to the Freeman hospital at 2 days old, and this is where her heart journey began. The team at the Freeman diagnosed Hope with a complex congenital heart defect which meant a lifelong plan of care to aim to give her the best quality of life with only half a heart.

The normal heart has two pumping chambers to drive the blood around the lungs and the body, in the case of Hope, one pump has to do the work as that's all she was born with. Hope underwent open heart surgeries and catheters (putting wires in the heart to test and improve the pipes and pump) throughout the first 3 years of her life to get her heart pipes and pump to function in the best possible way. Thanks to the team and her family support, Hope has not been back into hospital for surgery since. The pump is doing a great job. Hope takes regular medication and attends follow up checks with her cardiologist to keep a close eye on her heart health.

Hope is a footballer. From the age of 6yrs she has developed into a leading striker for her club. Her passion and commitment to her sport is obvious when talking to her. "I love my team" and this is what gets me there to training and games when sometimes it feels too much. Her heart rarely affects her or the way she takes on sport. She can't tell the difference most of the



time. "I just get more tired than everyone else, that's it". Hope has learned to self-regulate her tiredness when training or playing a match. She does this by taking some deep slow breaths and getting a drink. She gets extra training and games at the Improtech football academy where they have been very successful in the school's league. Her huge appetite means she has enough energy on board to tackle the intensity of the training session after a busy day at secondary school.

Her "no pain, no gain" attitude sometimes has her family

concerned but they have learned to trust that Hope knows her body very well and she will let them know if something feels not right.

Her Nanna will often try to put Hope off playing sport through worry of her becoming unwell. But Hope does it anyway!

Hope is honest and open about her heart with people she knows. Her friends have an understanding that she has a different heart to them and only has one pump. Her scar is a bit of an issue for Hope, but only with people she does not know. Her peers have asked about the scar and her open honest answer is simple and to the point to detract from any further attention. But with strangers, this is different, so she keeps it covered up.

Her football coaches, Eddie and Chris, are like proud fathers when they talk about managing Hope in their team and understanding her heart condition. At first, when Eddie met Hope aged 11yrs and her family, he was apprehensive about what this meant to Hope and her football abilities. The team quickly went about undertaking some life support training and fundraising for a defibrillator to be at hand in the training ground. This empowered the coaches to support Hope to participate in the thing she loved to do and was good at. The coaches have worked with Hope to build her stamina, this has taken time, but her athletic capacity on the pitch has



**Many thanks to Hope and family for sharing their story.**



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