

Mister Marvellous

*The long and
winding road*



Introduction

“Mister Marvellous” was written by Rob, a member of our patient community. The short story struck us as a real example of what it’s like to be diagnosed with heart failure but also what it’s like to live with it. Mister Marvellous takes you through the jolt of being told you have a life-changing condition to the rollercoaster of challenges and opportunities faced by those living with their heart failure. For us, the morale of the story is that if you take control you can manage it, life is never easy but if you believe you can do it you will.

The Pumping Marvellous Foundation is the UK’s heart failure charity and is led by patients like you and me.

Nick Hartshorne-Evans
Founder and CEO

MISTER MARVELLOUS

"My name is Rob and I am a husband, father and a grandfather, an educator and a storyteller, an owner of an inefficient heart and a big collection of story books. I have many good things in my life, like my family, friends and colleagues, each one of whom is like a book full of stories. My failing heart has given me the chance to see all these things and people with new eyes, with the vision of my 'new normal'. I am not defined by my condition, but transformed by it..."

One minute we are fine and then, gradually or dramatically, it all starts to change. It could be with a sudden collapse or a slow deterioration. However it comes upon us, heart failure makes its presence felt by hook or by crook.

Through the long and winding road of tests, educated guesses and many appointments with cardiac specialists we arrive at that eventual and potentially-life changing diagnosis. Sometimes, we also might find ourselves at a point where choices and decisions have to be made about some form of surgical intervention, to repair or remove or replace some part of our heart's architecture.



THE LONG AND WINDING ROAD

Hopefully, by now, we have found someone, from within the ranks of the many health professionals we have been getting to know with whom we can really relate to. This person could be our **GP** or a **heart failure nurse** or a **cardiologist**. It could even be a friend who has offered us support on a deeper level than we could have hoped for. And yet again, such help can come from a supportive organisation such as the **Pumping Marvellous Foundation**. Even a quick glance at their website will show the scope this outfit offers to over a thousand online members.

Then there is the experience of the starting to live in a different way, in order just to survive. Most of us who live with inefficient hearts, will have to begin a regime of medication that will become part of our lives forever. There might also be substantial lifestyle changes around diet and exercise. And for some of us there is the prospect of the aforementioned surgical intervention.

Often things get worse before they improve. Starting on a range of medications can, initially, make us feel rough. The tests we undergo may bring stress in various forms. Our moods can change. We may tangle with some form of depression or an altered self-image.

MISTER MARVELLOUS

The road to surgery, for example, can be an emotionally charged period of time. When I had my first surgery, over twenty years ago, I kept a journal of the experience of anticipation and fear. I took the step of letting my elder daughter know where this book was kept, just in case I didn't make it. I wanted her to have something tangible to remember me by.

Everything, in these circumstances, can seem to come down to a singular moment, a particular day, a significant time when we have to face up to a big event and just take our chances. With my first surgery, they could give me no 'survival' percentages, but the second intervention, some eight years ago, thanks to the superb work of the cardiothoracic surgeon **Samer Nashef**, of **Papworth Hospital**, and his devising of **EuroSCORE**, my second team of surgeons were able to give a very accurate survival percentage.

The sheer beauty and ecstasy of waking up after surgery is hard to describe. To come round and to be simply asked if a cup of tea or coffee would be in order is to know what the music of heaven sounds like... just to be alive is the greatest of treasures!



Once the initial euphoria is over, the rugged road to recovery begins. The physiotherapists come to sort us out, the anaesthetics have to wear off, we may even have to learn how to walk unaided – what next! Returning home can be unexpectedly difficult, as we have had to leave the womb-like warmth of the nurturing hospital environment. And then there are all those well-meaning family and friends who want to impress on us every kind of support, whether or not we wanted it in the first place...!

But then, if luck is on our side, we begin to feel revived, refreshed and renewed. We may never be quite the same again. Running a marathon may have quietly vanished from our usual list of things to do. But, amazingly, for some people who are redefining their lives after a diagnosis of heart failure, running a marathon is exactly what they do!

We can now make decisions about how we are going to live from here on in. It really can be a case of 'not counting the days but making the days count'. We can be powerful, we can choose to live an 'on purpose' life. I believe that if, however, we opt to be the 'victim', we shall have wasted such a lot of people's efforts on our behalf. For me to play for sympathy would be crass in the extreme.

MISTER MARVELLOUS

And so we find ourselves back where we started. But now we may take medications every day, we may have been surgically repaired, we may have implants, plus a range of unusual restrictions.

But our choice is ultimately a simple one. Red, that great character from the film **'The Shawshank Redemption'** puts it neatly when he states that 'we can either get busy dying or get busy living'... I'll go for the option of living, even with heart failure, if that's OK with everyone else...? And by living, I really mean relating. For if I had to describe the one thing that heart failure has done for me that I'm actually happy about, it is the effect it has had on all my relationships, with whomever. I treasure them all, I endeavour to make them work for everybody's benefit. My cardiac experiences have given me such an appreciation of the value of others, an awareness of what people can achieve. Because of what I have been through, I can wholeheartedly agree with that YouTube film title **'People Are Awesome'** – yes, they are! And now I can truly see that through the prism of my reconstituted heart....

ROB M

Heart Failure Patient



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heart failure aware



help for hearts (closed support group)



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