Living with heart failure: A patient perspective

Nick Hartshorne-Evans
United Kingdom
Nick Hartshorne-Evans

Heart Failure Patient
Founder and CEO of The Pumping Marvellous Foundation UK

President of iHHub
The Global Heart Failure Hub
Content

- Putting HF into context
- The Patient Community Voice
My experience – my jigsaw BC

My life was going really quite well
My experience – my jigsaw AD

Big messed up jigsaw puzzle
My experience – building the jigsaw

My corner pieces were: survival, belief, attitude and knowledge
My experience – finding the edges

My edges were informed opinions around my belief, attitude and knowledge
My experience – matching the pictures

My jigsaw was formed by using my experience of life, recognising what would work and what wouldn’t.
My experience – missing pieces

The missing pieces, the gaps in my knowledge to achieve normality just like before
My experience – HOPE

Acquisition of missing pieces through researching the facts and a real belief in HOPE
My experience – the jigsaw man

My experiences, desire and my sheer drive shaped me into a new person. Putting together my jigsaw has shaped my thoughts, direction and given me the results I wanted.
My experience – the power of the jigsaw

So thinking bigger picture, what could happen if I shared my experience and how could this benefit other patients?
Many Patients, Many Perspectives are a Powerful Tool

Power of collaboration
Power of peer to peer learning
Power of the patient voice
Power of leadership
Power of ownership
Direct from the patient community

“It’s like growing old overnight without gradual ageing giving you the chance to get used to it”

- Andy, Heart Failure Patient
Pumping Marvellous Patient Educator

The Pumping Marvellous Foundation is the UK’s patient-led heart failure charity
“A marvellous group of patients who together do marvellous things.” www.pumpingmarvellous.org
Direct from the patient community

We polled our global online patient community and this is what they told us.
Direct from the patient community
Direct from the Patient Community
What did we do well?

• Acute patients feel looked after in Hospital
• HF nurses are invaluable
• Cardiologists generally treat the heart well
• Cardiologists are interested in advancing treatments
• Hospital support staff treat you with respect
Direct from the Patient Community
What would people like to see?

• Access to care and therapies needs to be equal
• Better initial engagement of patients in self management
• Better understanding of HF from non-cardiologists
• Better continuity of care
• Are the pathways followed? Patients look at pathways as well
• Speed up access to help and self learning.
• How you are dealt with in ER – Don’t you believe me? I have HF!
Direct from the Patient Community
What we could do better?

• Referral to the wider MDT
• Poor understanding of mental impact of HF
• Patient information is convoluted
• Poor general awareness of HF
• Who do I turn to the 364 days of the year I don’t see my cardiologist?
• Poor diagnosis delivery
By 2010 no British Rider had won the Tour de France

By 2015 Team Sky had won it 3 times with British riders

Their success stemmed from optimising every aspect of the ‘cyclists’ team

Who is the patients’ ‘Sir David Brailsford’?
(SKY CYCLING TEAM PRINCIPAL)