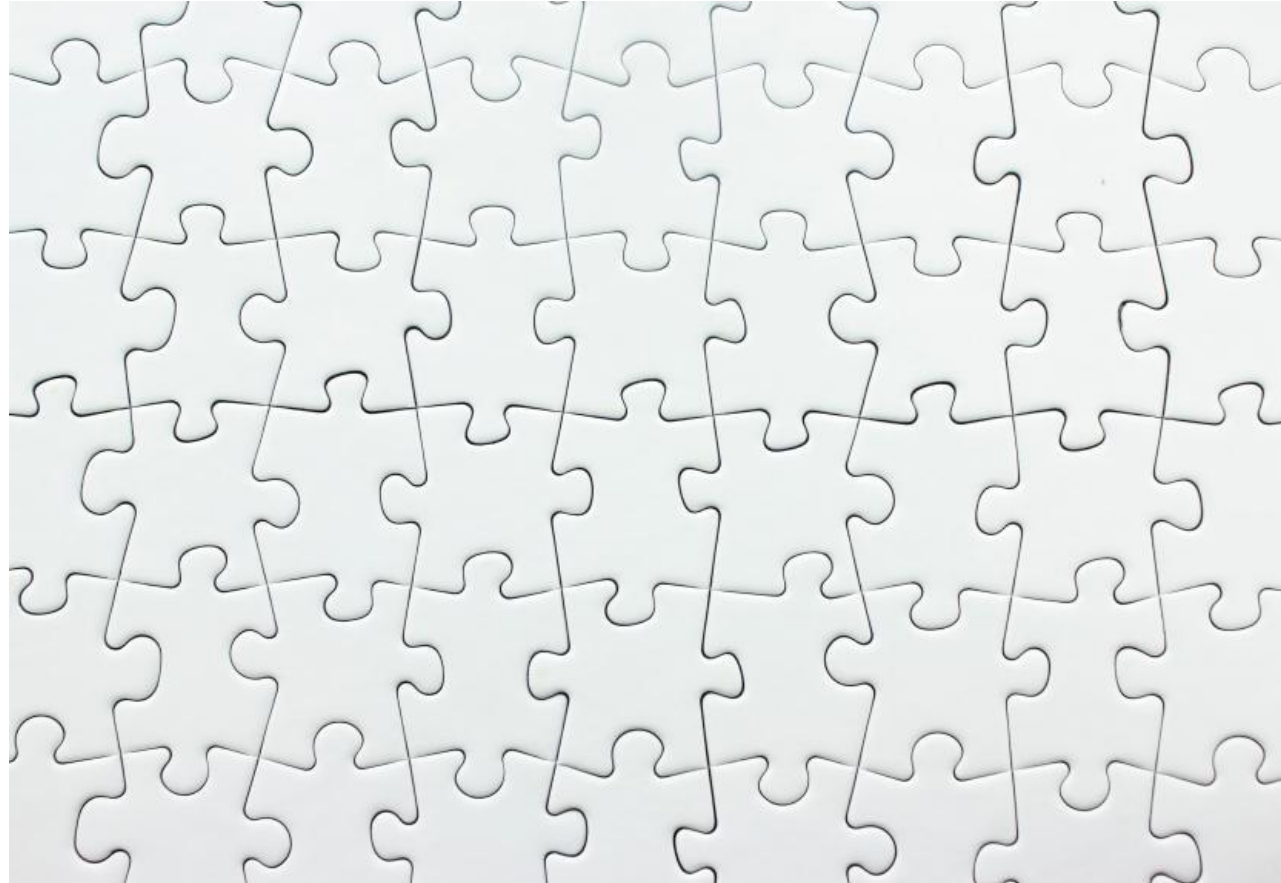


The Power of the Patient

My Jigsaw BC (before condition)



My life was going really quite well

My Jigsaw AD (after diagnosis)



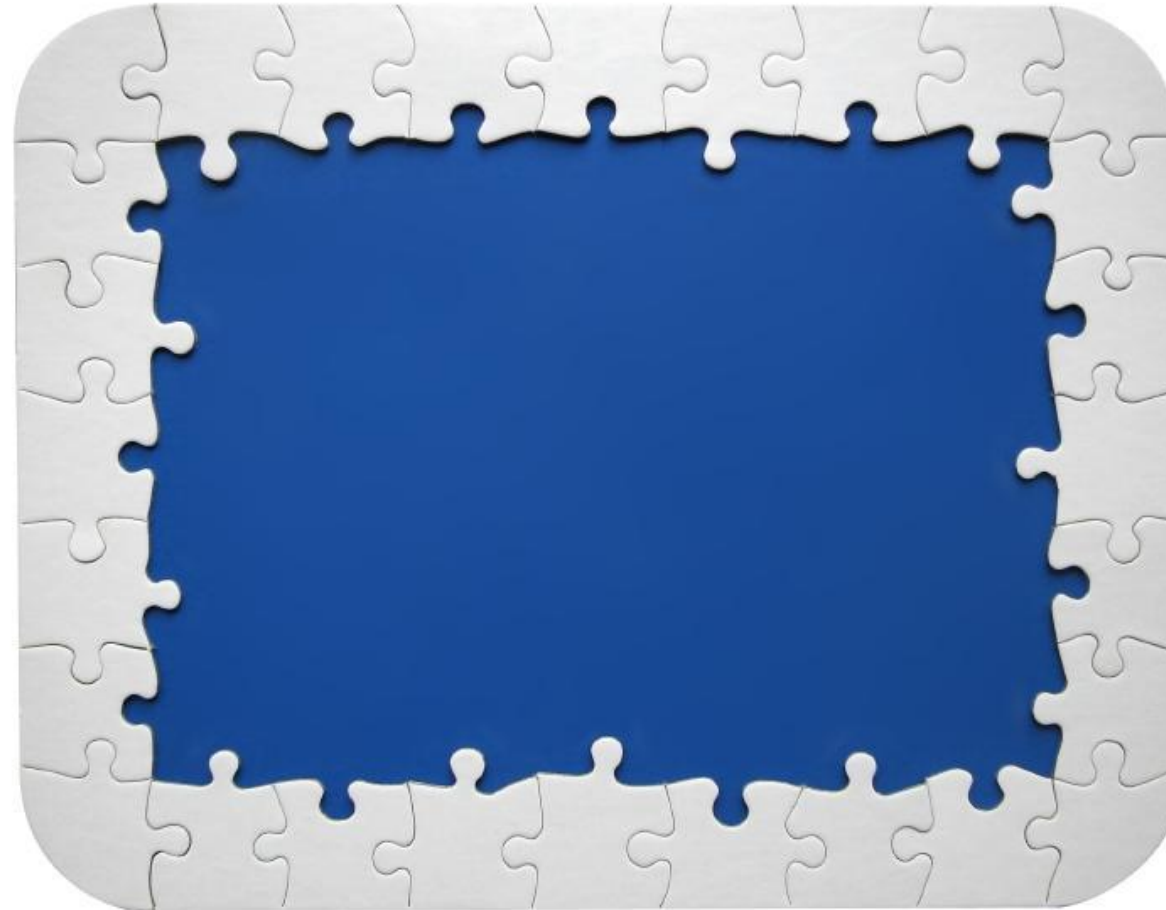
Big messed up jigsaw puzzle

Corner Pieces



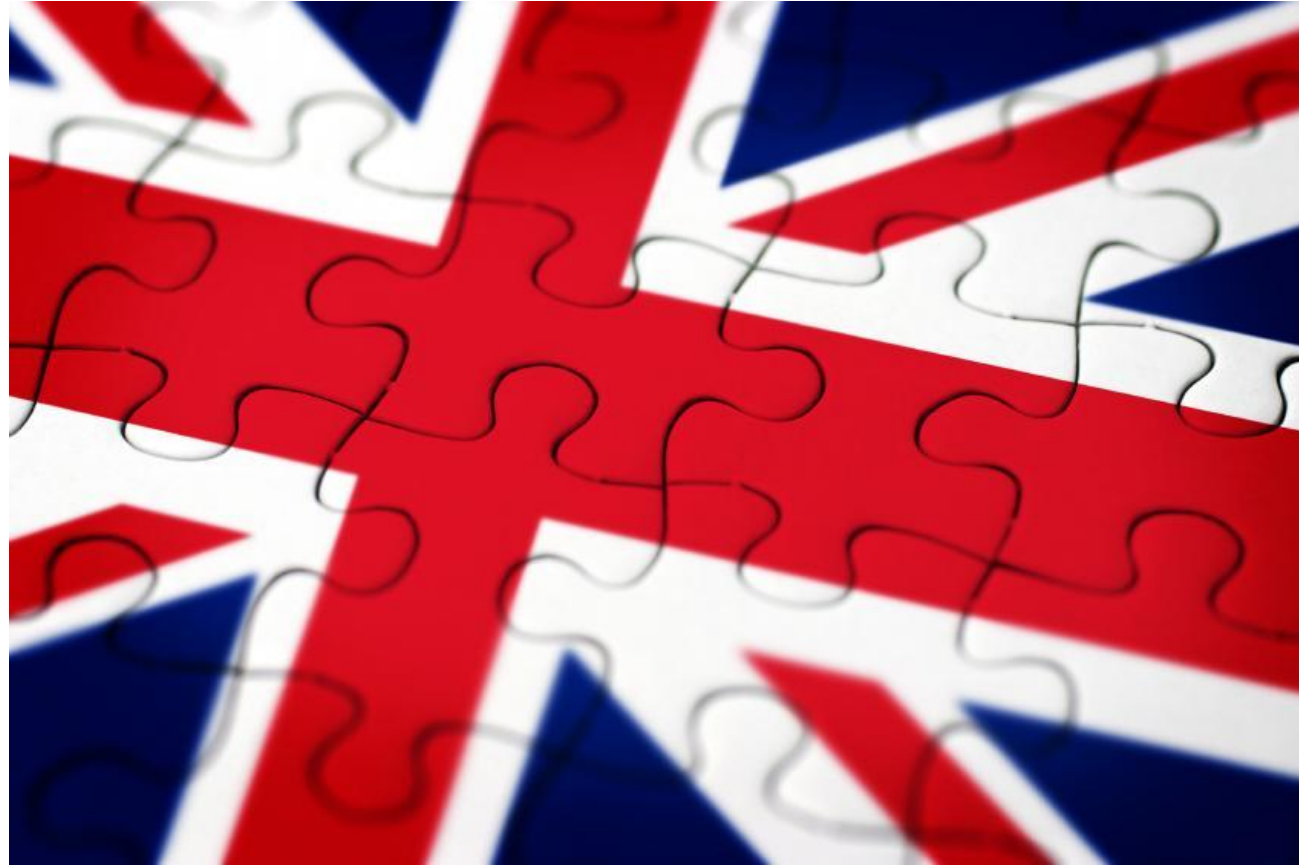
My corners pieces were: survival, belief, attitude and knowledge

The Edges



My edges were informed opinions around my belief, attitude and knowledge

Colour Combos and Pictures



My jigsaw was formed by using my experience of life, recognising what would work and what wouldn't

Missing Pieces



I was always on a mission to find the missing pieces, the gaps in my knowledge to achieve normality just like before

Research and HOPE



I tried to acquire my missing pieces through research around the facts and a real belief in HOPE. I never gave up.

The Bionic Jigsaw Man



I became a new person. My experiences, desires 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.

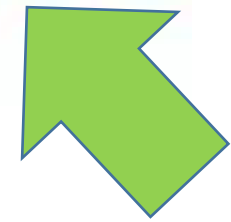
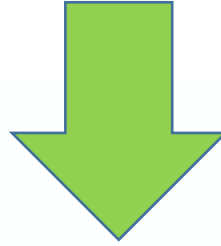
What were my challenges?

- Dealing with my mortality – it felt real
- Dealing with my uncertainty – I felt out of control
- Dealing with my loneliness – Nobody to help with my psychological challenges
- No support network – No visible group to help
- How do I manage when my nurse or cardiologist isn't there?

An opportunity

To address all those challenges and more

Its what heart failure is
about



This is a positive
word

The Power of the Jigsaw



So thinking bigger picture, what would happen if we assimilated my ideas?

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

What do we stand for?

- Mission
 - We give HOPE to heart failure patients and their families by **involving them in their own care** and advocating for them, giving them a voice. **We don't tell them**
- Aims
 - Building Awareness
 - Giving **HOPE** and **HELP**
 - Giving patients and families a **voice**
- Objectives
 - Increase awareness of the condition
 - Working to ensure people have the best and most appropriate **toolkit** for self management
 - Actually making a difference rather than just talking about it. **Patient driven Advocacy**

What do we do?

- Support
 - Patient information, heart buddy etc
- Advocacy
 - NHS, NICE, Academic, Political, Industry
- Self Management
 - Suite of products
 - Globally crowd sourced
 - **Coaching and development of soft skills (Engagement)**
- Access
 - Working toward **total patient access** for parity of care
- Awareness
 - **Patient designed** and patient led
 - Network of patient educators local, national, international (**expert creation**)
- Partnership
 - Develop with, not to HCP's to ensure information is in "patient speak"
 - Work with Industry and Academics to **add value** into their work

Our Patient Educators

Meet Andrew one of our Patient Educators



Examples of patient involvement (awareness)



'aware in the world' = Museo Sans Rounded 1000
'pumpingmarvellous.org' = Museo Sans Rounded 900

'#awarenessispower' = Museo Sans Rounded 900
'#heartfailure' = Museo Sans Rounded 900
'#HOPE' = Museo Sans Rounded 900
'@PumpingHearts' = Museo Sans Rounded 900
'pumpingmarvellous.org' = Museo Sans Rounded 900



pumpingmarvellous.org

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pumpingmarvellous.org

pumpingmarvellous.org

Examples of patient involvement (self-management)

AN EVENING WITH THE PUMPING MARVELLOUS PATIENT EDUCATORS

WITH SPECIAL GUEST ANGELA GRAVES

East Lancashire's own Heart Failure Queens Nurse who is retiring from service in September 2014

The evening will also include an evening meal and an opportunity to have a roundtable discussion with the Pumping Marvellous Patient Educators, who are heart failure patients from all parts of the country. They help the charity with giving HOPE to heart failure sufferers and their families.

No slides and computers this is all about you

DATE: 11TH SEPTEMBER

TIME: 5.30PM - 8.00PM

VENUE: JAMES HARGREAVES SUITE, BURNLEY FOOTBALL CLUB

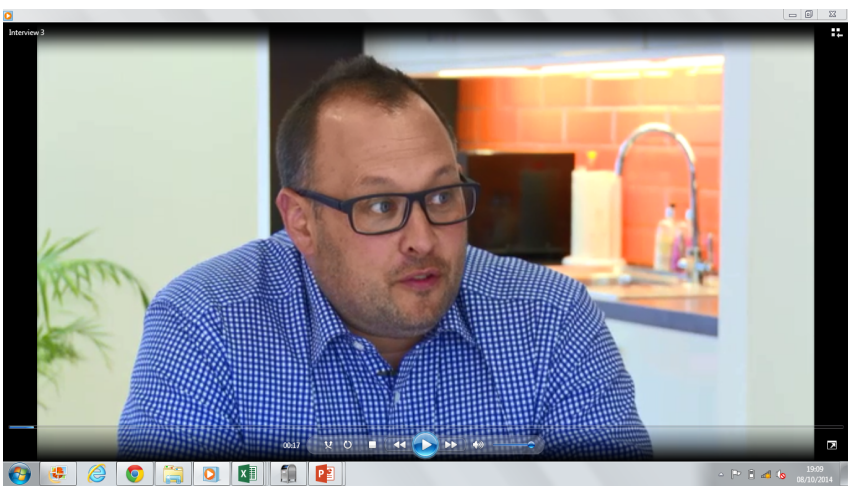
RSVP TO JACKIE LOWRIE ON 01254 358094



H.O.P.E.

A Patient's Story...

Examples of patient involvement (advocacy)



Examples of patient involvement (partnership)

East Lancashire Hospital
NHS

Palliative Care & Advanced Heart Failure



bettertogether



Classification Of Heart Failure Syndrome New York Heart Association

In order to determine the best course of therapy, physicians use the stage of heart failure according to the New York Heart Association (NYHA) functional classification system. This system relates everyday activities and the patient's quality of life.

Class I: Asymptomatic

No limitations of ordinary physical activity. Ordinary activity does not cause undue fatigue, dyspnoea, palpitation or angina.

Class II: Mild

Comfortable at rest. Slight or moderate limitation of physical activity. Ordinary physical activity results in symptoms.

Class III: Moderate

Although comfortable at rest, marked limitation of physical activity. Ordinary activity causing symptoms.

Class IV: Severe

Symptoms at rest. Inability to carry on any physical activity without symptoms or cardiac insufficiency.

Severity applies to the symptoms not necessarily to prognosis. Less than ordinary physical activity is defined as climbing one flight of stairs or walking one block.



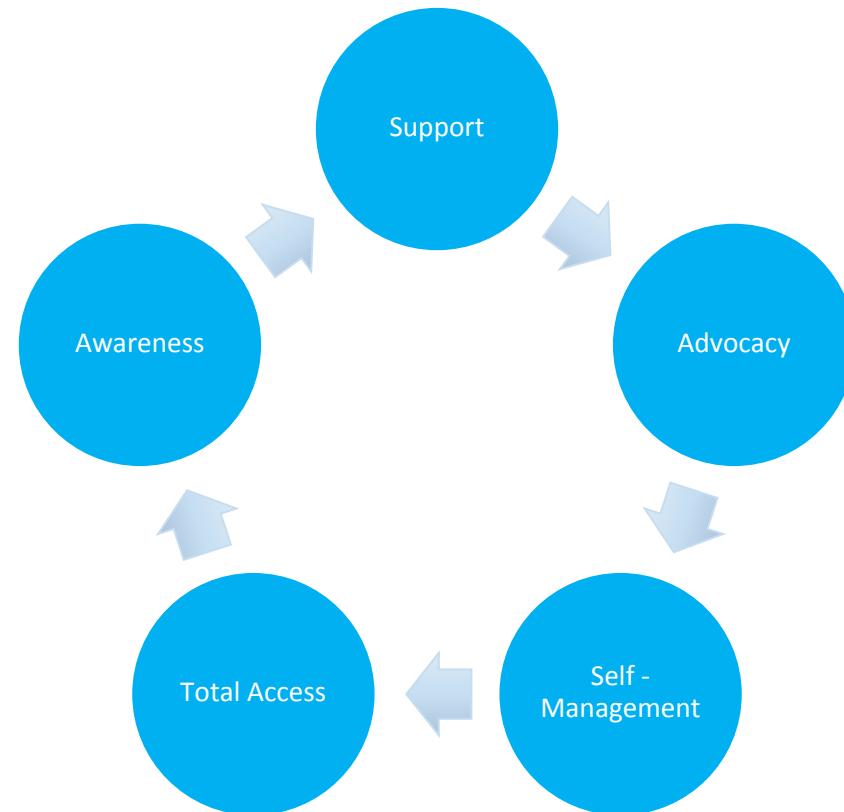
WE ARE
MACMILLAN.
CANCER SUPPORT

East Lancashire Hospital

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How does this fit into the Global Picture?

It's the same wherever you are



Take home messages for building a successful Heart Failure Patient Group

- Build character into your brand
- Clearly define your aims and objectives
- Be patient led, recruit motivated people
 - Make sure patients and carers come up with the ideas, just police them
 - Reward involvement
- Understand your universe
 - HCP relationships
 - Industry relationships
- Invent and innovate and I mean really innovate
- Identify solutions not problems, look in to the problem

Take home messages for building a successful Heart Failure Patient Group

**Don't eat an
elephant at once**

**Be known to DELIVER
tangible results**

**Don't be afraid to look
outside the health economy
some of the best ideas come
from other industries e.g.
Apple, Amazon, Ebay etc**

**Be an excellent
communicator
and learn from others**

**Understand the
power of digital**