Fiona Bardon

MY JOURNEY THROUGH THE STROKE CONNECT SERVICE AND BEYOND

Disclosure Statement

There are no conflicts of interest to declare

Post Hospital Care

- When I had my stroke in August 2019 I was discharged home with no medical supports
- I had great support in hospital but upon discharge issues emerged
- I had a lot of appointments to keep on top of but nobody to help with scheduling
- No psychological support

How was I feeling?

Confused **Frustrated Anxious** Low Mood Accepting Mis-**Afraid Nervous** Guilty Grateful understood Isolated **Untrusting** Vulnerable **Elated** Weak

Hope...

▶ Lack of information

- Rehabilitation was very intermittent
- Difficulty in finding support
- ▶ Finding Irish Heart Foundation Nov 2020

Irish Heart Foundation

- Life After Stroke IHF private facebook group
- Online exercise class (during covid and continues)
- Easy communication with IHF staff who signpost, research and communicate with us about services in the community
- Provide services and support that we are not receiving – counselling, information talks and courses

Irish Heart Foundation

 WhatsApp group for Young Stroke Survivor Network members

- In-person exercise class, coffee and chats with people who understand and are non-judgmental
- Peer Support people my age, older
 & younger who I can relate to and build friendships with

What else helped me in my recovery?

▶ Diet, exercise and building a routine

- Counselling
- ► Acceptance recovery is non-linear
- ▶ New "colleagues" stroke survivors, brain injury classmates
- Acquired Brain Injury Ireland, National Rehabilitation Hospital and Headway

Services and supports needed for other stroke survivors going forward:

- ▶ Treat the patient, not the condition
- ▶ Provide information of where patients, carers and their family can go to for help. Explain who does what – S.L.T. to O.T. to V.T.
- New difficulties can emerge as life progresses mental health, financial, family or relationships, physical as an after effect of stroke. We need a longer-term support plan
- ▶ What is "better" ?

Key Learnings For Me...

Proper funding saves money long term

► Early rehabilitation and timely interventions means less pressure on staffing and resources in the future

Listen to and reflect on the patient experience to effect change

Signposting to other supports is key

Key Learnings For Me...

- ▶ F.A.S.T. campaign inclusive of all ages
- ▶ Be mindful of non-F.A.S.T. symptoms especially in the younger stroke survivors
- Effective communication don't assume understanding, ensure understanding.
- Access to professional support and expertise referrals

Giving back...

▶ As patients are discharged home, we HAVE to fight for ourselves regardless of whether we can form thoughts, speak, read or write. Once we are deemed physically fit, we are discharged and left to fend for ourselves.

▶ Advocacy

▶ Trying to make a difference

▶ Peer Support