



Fiona Bardon

**CHRONIC DISEASE FROM A
PATIENT PERSPECTIVE**

August 2019

- ▶ I woke up feeling sick
- ▶ Vomiting
- ▶ Mum found me having a seizure
- ▶ Fire brigade came, followed by ambulance

My stroke symptoms

- ▶ Vomiting
- ▶ Seizure
- ▶ Blurred/no vision
- ▶ Was unable to answer questions or speak coherently



My hospital stay

- ▶ Emergency Dept. – scanned and diagnosed
- ▶ Woke up in ICU
- ▶ Fractured shoulder
- ▶ Was assessed but I don't really remember
- ▶ Spoke to epilepsy nurse before discharge

Post Hospital Care

- 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?

Accepting

Confused

Frustrated

Anxious

Low Mood

Grateful

**Mis-
understood**

Afraid

Nervous

Guilty

Elated

Weak

Vulnerable

Isolated

Untrusting

Continued Difficulties...

- ▶ Lack of information
- ▶ Rehabilitation was very intermittent
- ▶ Difficulty in finding support

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, stroke connect service, information talks, nurse helpline, and courses

Irish Heart Foundation

- WhatsApp group specifically 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
- ▶ Acquired Brain Injury Ireland, National Rehabilitation Hospital and Headway

Services and supports needed for patients going forward:

- ▶ **Treat the patient, not the condition**
- ▶ **Provide information of where patients, carers and families can get help.**
- ▶ **Explain who does what**
- ▶ **We need a longer-term support plan. Difficulties can emerge long after a diagnoses as life progresses – mental health, financial, family or relationships, physical.**
- ▶ **What is “better” or a “good life” ?**



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
- ▶ Location shouldn't dictate care
- ▶ Listen to and reflect on the patient experience to effect change

Key Learnings For Me...

- ▶ Effective communication – don't assume understanding, ensure understanding.
- ▶ Access to professional support and expertise – referrals
- ▶ Signposting to other supports is key

Final Thoughts

- ▶ As patients are discharged home, we HAVE to fight for ourselves - regardless of whether we can form thoughts, speak, read or write.
- ▶ Advocacy and trying to make a difference
- ▶ Peer Support
- ▶ Thank you to all of you!