NHS Ayrshire & Arran



Meeting: Ayrshire and Arran NHS Board

Meeting date: Monday 30 January 2023

Title: Patient Experience: Karen's story

Responsible Director: Joanne Edwards, Director of Acute Services

Report Author: Laura Harvey, QI Lead, Patient Experience

1. Purpose

This is presented to the Board for:

Awareness

This paper relates to:

- Government policy/directive
- Local policy

This aligns to the following NHSScotland quality ambition(s):

- Safe
- Effective
- Person Centred

2. Report summary

2.1 Situation

Karen, a staff member, wanted to share her experience with a chronic health condition and the impact the right treatment and procedure can have. She also relays her experience as an inpatient following recent surgery in Ward 6 at University Hospital, Crosshouse

As our Volunteer Manager, her experience was also an excellent learning opportunity for her role.

2.2 Background

Karen's story illustrates the journey she faced prior to successful treatment and how much impact it can have on all aspects of a patient's life.

"You never know what someone is dealing with behind closed doors. So be kind" Annon.

2.3 Assessment

Karen's story demonstrates that often our patients have gone through a lot prior to reaching our services and it's important for staff to recognise that to ensure we give the patient the best experience.

What may be considered a simple routine procedure for staff, could literally change our patients' lives and Karen's story illustrates this well.

Conversely, when a small thing goes wrong or the patient doesn't feel their care is person centred, it can also have a massive impact as this is a major life event for the patient.

2.3.1 Quality/patient care

Understanding our patients' health journeys allows staff to provide true person centred, compassionate care.

2.3.2 Workforce

The biggest impact on patient experience is staff – their interactions and the quality of the care they deliver.

2.3.3 Financial

No financial impact.

2.3.4 Risk assessment/management

No identified risk.

2.3.5 Equality and diversity, including health inequalities

An impact assessment is not required as the individual sharing the story has given consent and any impact on others will be individual.

2.3.6 Other impact

Best value

Karen's story demonstrates the wide impact chronic poor health can have and the wide reaching positive impact of successful treatment.

Safe, Caring & Respectful

This story fully complies with our corporate objectives and highlights the importance of applying them to every patient throughout their care journey.

2.3.7 Communication, involvement, engagement and consultation

This story has been shared with the staff and services involved.

2.3.8 Route to the meeting

This story has not been heard at any other meetings.

2.4 Recommendation

For awareness. Members are asked to read and listen to Karen's story for information.

3. List of appendices

Appendix 1 - Patient Experience: Karen's story

Appendix 1 Karen's Story

My story begins like many others. Chronic pain for as long as I can remember. A sense of hopelessness and a fear of resigning myself to the fact that this is what life is going to be like. Painting on my 'happy face' and just getting on with it.

I was diagnosed with endometriosis and fibroids when I was 19. Having spent much of the previous five years with crippling period pain, which often lasted all month, it was a relief to know there was a clinical reason for my experiences. Whilst it didn't give me a cure, I was able to rest in the knowledge that it 'wasn't all in my mind'.

When I was 25 years old, I was diagnosed with infertility. This was hugely devastating due to my desire to have a family. Years of IVF and other fertility treatments followed, yet this wasn't the chosen path for me. Whilst traumatic, I was given a reprieve from my chronic symptoms due to the fertility treatment – and it wasn't until I was around 33 years old that the pain was back again – and worse than ever before.

Like many women, I got my head down, tried as many alternative therapies as humanly possible, and resorted to over the counter pain relief on the days I wasn't able to function without it. But the pain only got worse, along with the increasingly long list of symptoms such as continual bleeding, headaches from anxiety and stress, and further down the line, a diagnosis of depression. Painting on the 'happy face' was no longer something I had the strength to do. I guess you could say, I felt like the condition had 'consumed' me.

In 2020, I started to experience a worsening in bleeding between my monthly cycle, and the pain had changed. Something just didn't feel right. I contacted my GP who immediately referred me to Gynaecology for investigation. This was the first time I met Dr Inyang, and I knew from this point forward, there was hope for a better quality of life for me.

Dr Inyang was tasked with exploring the cause for my excessive bleeding which was the result of cervical erosion. But he wasn't solely interested in that. He had looked at my case notes, spanning many years and documenting several investigations and procedures to remove fibroids, cysts and endometrial tissue. And he was the first professional to demonstrate a desire to do something about this. He wanted a better quality of life for me. And he set the wheels in motion, that very day, back in 2020, to ensure I was given the chance of a pain free future.

Following a number of consultations, Dr Inyang and I agreed the best course of action would be to undergo surgery to remove my uterus, cervix and fallopian tubes. Was I scared? Yes! But I knew what I was facing, and after almost 20 years, I was ready. And whilst I faced a longer than usual wait for surgery due to service pressures post pandemic, I was able to keep in regular contact with Dr Inyang – enabling me to ask any questions I had about the surgery. But also to express how much pain I was in by this point in my journey. And throughout it all, he gave me hope.

In July 2022, I was admitted to Crosshouse Gynaecology Department for my total hysterectomy. And this is where my story changed. From the moment I was admitted, until the day I was discharged, my experience was so positive. I was treated with dignity. Respect. Care and Compassion. From the Consultants who spoke to me pre and post-surgery, to the wonderful nursing team and auxiliary staff, who helped me get out of bed and on my feet again. Their encouragement was so empowering.

Here we were, fresh out of the pandemic, and the clinical teams around me were nothing short of outstanding. No ask was too much. No question too trivial.

In a world where there is pain and suffering, where there is fear and hopelessness – we must recognise the beauty in those who can really make a difference. My life has been turned around. I feel like me again. And I cannot thank Dr Inyang and his team enough. Sincerely, and always, thank you.