

NHS Ayrshire & Arran



Meeting:	Ayrshire and Arran NHS Board
Meeting date:	Monday 4 December 2023
Title:	Patient Story – Claire’s MS Journey
Responsible Director:	Claire Burden, Chief Executive
Report Author:	Laura Harvey, QI Lead for Patient Experience

1. Purpose

This is presented to the Board for:

- Discussion

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

Claire’s ‘patient story’ describes the difficulties and delays she encountered in her journey towards eventual diagnosis of Multiple Sclerosis (MS). Her story also demonstrates her positive experience once she was referred to the Specialist MS Team at the Douglas Grant Rehabilitation Centre, Ayrshire Central Hospital.

2.2 Background

Claire was referred to a Neurologist by her GP after experiencing symptoms consistent with MS. Claire had an MRI scan that same month. She had heard nothing following it and assumed ‘no news was good news’.

At Claire’s follow-up appointment with the Neurologist, 11 weeks after the MRI scan, she was told that the scan results showed a deterioration from a previous scan in 2008 that was indicative of MS and a lumbar puncture would be required to confirm.

A lumbar puncture was carried out and when Claire called requesting the results she was told the Neurologist had reviewed the results and would see her at a follow-up appointment in three months’ time. A letter of the findings would be sent to her GP.

At a routine appointment with her GP a couple of days later, Claire asked for the results of the lumbar puncture and her GP was able to confirm the diagnosis of MS. The GP was very apologetic that the Neurologist had not seen Claire to provide her with a diagnosis and Claire worried that the Neurologist had not planned on sharing the diagnosis until the review appointment, three months hence – seven months after her initial appointment.

Claire felt let down by the service. Her understanding was that referral to an MS Nurse should be within 2 weeks of diagnosis, however she had to assume that she wouldn't be referred to the MS nurse until she was informed of her diagnosis by the Neurologist at her next appointment.

Claire shared her disappointing experience on Care Opinion, which led to her referral to the specialist MS Service within the Douglas Grant Rehabilitation Centre.

Claire's experience changed dramatically once she was referred to the MS Service. With the multidisciplinary Team of AHPs, Physiotherapists and support staff working together with Claire to provide safe, effective and person-centred rehabilitation.

2.3 Assessment

Claire received excellent patient centred care, tailored to her specific needs, once she was referred to the specialist multidisciplinary MS Team at the Douglas Grant Rehabilitation Centre.

However there were delays in Claire's healthcare journey which caused her a great deal of anxiety and opportunities for improvement within the Neurology Service were highlighted. Our Neurological Service is provided by NHS Greater Glasgow & Clyde (NHSGGC) and delays in patients receiving consultations and results has been previously identified.

Through collaborative working with NHSGGC and NHS Forth Valley a number of work streams have been progressed in the last few months to improve the current service we provide and also to address the long waiting time for new out-patient consultations within the neurology service. These have included;

- Mutual Aid has been secured from the consultant neurology team at NHS Forth Valley. The team at NHS Forth Valley have managed a number of patient referrals for investigation, clinical review and advice. A number of telephone consultations have also been carried out. Since July 2023, 85 new patient referrals have been managed in this way.
- Out-patient clinical consultations have been undertaken by an external provider who were able to provide face to face consultations from NHS Ayrshire & Arran hospital out-patient departments. Since April 2023, 645 new patient referrals have been managed in this way.
- The consultant team from NHSGGC have introduced an Active Clinical Referral Process for long waiting patients. This exercise involves a detailed review of previous clinical history and investigations enabling new patient referrals to be streamed into cohorts according to the presenting complaint.

Through joint working with NHS Forth Valley and the external provider, we can direct the most suitable patients to each service and prioritise those whom the visiting NHSGGC consultants require to see in Ayrshire. A number of cases have been suitable for consultant advice alone.

Since this new process was commenced in July 2023, 34 patients who had significant waits were discharged with consultant advice. A further 382 patients were streamed into cohorts and progressed via the work streams detailed above.

The consultant neurologists are now applying the Active Clinical Referral Process for new referrals, allowing a proportion of patients to be managed through consultant advice alone. This process also ensures that patients who require clinical consultations are allocated appropriately when the referral is received.

- The Public Health Service has also commenced a corporate needs assessment of the service. Chaired by the Director of Public Health, a Health Needs Assessment Group has been convened in relation to Neurology. Claire's story has been shared with the Director of Public Health. There has been good clinical engagement with this exercise to date.

As a result of Claire's experience, and that of other patients who have experienced delays or were unhappy with their neurological care, there has been significant improvements made to this important service.

This highlights the importance of using patient experience to drive positive transformations.

2.3.1 Quality/Patient Care

Claire's story highlights the value of both positive and negative patient feedback. It reinforces the true value of the patient's voice and how it can help to transform how we deliver services.

Similarly, positive feedback can be used to provide reassurance to future or current patients and is an important indicator for staff to measure the effectiveness of their services and contribution. Furthermore, it can promote the opportunity for other teams to learn from excellence. That way, improvement can be demonstrated not just in the service being reviewed, but in the wider organisation.

2.3.2 Workforce

Staff experience has a direct and significant impact on patient experience.

Sharing positive and negative feedback with staff across the organisation demonstrates an open, honest and transparent approach to improvement and this encourages other teams and individuals to adopt a similar approach in their improvement journeys.

2.3.3 Financial

No financial impact

2.3.4 Risk assessment/management

No risk identified.

2.3.5 Equality and diversity, including health inequalities

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

2.3.6 Other impacts

Compliance with Corporate Objectives

- Safe, Caring and Respectful

2.3.7 Communication, involvement, engagement and consultation

This patient story is presented for awareness and to support learning and improvement across our services, particularly in minimising delays in diagnosis and subsequent treatment.

2.3.8 Route to the meeting

Claire's story has been shared with the staff directly involved.

Claire's story has also been shared with the Director of Public Health, to inform the work being undertaken by the Health Needs Assessment Group and subsequently shared with colleagues in NHSGGC and the Head of Health Record Services, NHS Ayrshire & Arran to ensure this feedback was considered and utilised to drive change.

2.4 Recommendation

Members are asked to watch this story, discuss the outcomes and to take assurance from how this has been shared for learning and to drive change.

- Discussion – Examine and consider the implications of a matter.