

## **PE1566/F**

20th May 2015.

PEO1566 : National Service Delivery Model for Warfarin Patients.

Dear Convener,

I refer to the above Public Petition. As petitioner I thought it imperative that I provide an insight into the difficulties and challenges faced by patients who self present to self test/ self manage their warfarin levels when deemed safe and effective by a health care provider.

I am an adult congenital heart patient. I, like many of our diverse, growing population, in both paediatrics and adulthood, am on Warfarin to thin my blood. I am a wife, a mother, I am employed and I lead a healthy lifestyle after the implantation of two metal heart valves, an aortic root enlargement and a pacemaker. I only recently had a further open heart surgery. My biggest fear is having a stroke. After my first open-heart surgery, I was carried by my husband to attend my anticoagulation service. My family were advised that the service did not provide home visits.

I requested to work with my local care providers to self-test and, if safe and effective to do so, self-manage my anticoagulation levels. I was refused; the explanation was not person-centred, with no-one actively listening to my request. It was at the directive of Greater Glasgow and Clyde Health Board, because "I don't work away from home".

A few weeks later I was also refused an urgent appointment at my anticoagulation clinic which an out-of-hours GP requested me to obtain after he prescribed me a course of antibiotics which would increase my anticoagulation levels, and which if not checked could prove fatal. With our nursing staff and local clinic reduced, I found myself placed in a Catch-22 situation. Had I not been fully informed and thus able to challenge the decision, the outcome could have been devastating. My concern is for those patients who would not have questioned this decision.

I went on to meet with a hematologist at Gartnavel Hospital who agreed that my time in therapeutic range would improve with self testing, I would be patient number 31 to do so. I agreed to speak to my GP to provide my test strips on prescription, this was well supported and I was provided my machine by our charity as this is not freely available. The next day I received a call from Gartnavel anti-coagulation nurses to advise funding had been stopped for self testing training. I continued to challenge writing many letters to the then Public Health Minister "Michael Matheson" who advised this was the decision of individual Health Boards.

I met with the Clinical Manager of Anticoagulation Services who provided me with a true person centred approach and support as did the nurses at my local anti-coagulation clinic. Last year I met with the Chief Executive of GGCHB. This led to a nurses day where I was supported by John Fegan, the Chairman of The Scottish Association of Children With Heart Disorders and another adult congenital heart patient who gave an inspiring insight into her condition and self testing. Standard

Operating Procedures were drawn up for young adults moving from the Royal Hospital for Sick Children to adult services, whose parents and carers are taught to self test if they are prescribed warfarin in paediatrics. This standard procedure will ensure an uninterrupted care pathway for GGCHB patients not only in our congenital heart community but also other young adults with other long term conditions who also require warfarin.

In September 2014 I began self testing, my time in therapeutic range has improved and I am able to take control and gain an acceptance of my long term condition. Self testing proved invaluable recently in hospital, due to multiple surgeries access to my veins is difficult. I was able to test my own levels safely and effectively.

However, there are approx 80,000 warfarin patients in Scotland situated within 14 regional health boards; this petition is to request a “ National Service Delivery Model Of Care” for all warfarin patients who self present to self test/ self manage their warfarin levels. We wish for them to be given that person centred care approach in line with The Scottish Government 2020 vision, which details “there is a focus on prevention, anticipation and supported self-management”. We wish to embrace the key objective of The Self Management Strategy “Gaun Yersel” written by patients with long term conditions for patients with long-term conditions in Scotland, written to cheer a person as he or she embarks on a challenge, where people can access timely and appropriate information and support to make well-informed decisions about their life.

I refer you to the latest evidence and recommendations, which has not been updated by The Scottish Government's Evidence Note:

SIGN Guideline 129: makes the following Grade A recommendation: “Self monitoring and self dosing is safe and effective and can be considered for some patients”.

The Royal College of Physicians Edinburgh Consensus Statement states that :  
“Anticoagulant control may be improved by near patient testing and engaging patients in their own care; patient education should be supported at every stage”.

NICE: recommends “the use of some coagulometers by people taking long-term anti-blood clotting therapy if they prefer and are able to effectively use this type of monitoring”. (see guideline published in September 2014).

We ask the petitions committee to support our petition and change the lives and care pathways of warfarin patients in Scotland, whilst providing support, education and resource to our health care providers.

Kindest Regards,

Mary Hemphill