

# Endometriosis

Endometriosis is a long-term condition where tissue similar to the lining of the womb grows in other places, such as the ovaries and fallopian tubes. It can cause a lot of pain and significantly impact the lives of those suffering from it.

## You Said



The issues around endometriosis care in Northern Ireland were raised with the Patient and Client Council (PCC) by a member of one of our Local Advisory Committees (LAC).

The PCC became involved with the Endometriosis Support Group, a regional service user group. We learned that:

- Numbers of severe (Stage IV) referrals to the endometriosis clinic in Belfast were increasing;
- Over one-third of referrals were for people suffering from severe endometriosis, with a majority of these requiring operations – long waiting times for operations; and
- Women with severe endometriosis often felt that they had been misdiagnosed and that their condition had been mismanaged by healthcare professionals.

## We Did



- 2013: Hosted a series of meetings and workshops with women living with severe endometriosis.
- January 2014: Hosted a regional symposium in partnership with the Pain Alliance of Northern Ireland, attended by the Minister for Health, decision makers, service users and professionals.
- November 2015: Facilitated two group discussions between service users and officials from the Public Health Agency and the Health and Social Care Board.
- April 2017: Co-hosted workshop with the Health and Social Care Board, including input from clinicians, service users and commissioners.

## What Happened



- June 2013: Health Committee recommended an integrated endometriosis centre to the Northern Ireland Assembly, to be based at one site and offer the full spectrum of medical and surgical treatments, alongside alternative therapies and counselling.
- 2017/18: Endometriosis specialist nurses recruited in the Belfast Trust (2017) and Western Trust (2018). A key part of this role will include education of GPs to support earlier diagnosis of endometriosis.
- 2018: Altnagelvin Area Hospital applied for accreditation as a local centre for the diagnosis of endometriosis and is currently recognised as a 'Provisional Endometriosis Centre' which will become a fully recognised Endometriosis Centre after a year if appropriate criteria are met. However, this is not a regional centre.

# Myalgic Encephalomyelitis (ME)

Patient and Client Council  
Your voice in health and social care

Myalgic encephalomyelitis (ME) also known as chronic fatigue syndrome (CFS) causes persistent fatigue which does not go away with sleep/rest, and affects everyday life. It is a serious neurological condition that can cause long term illness and disability.

## You Said



Hope 4 ME and Fibro Northern Ireland presented to a Patient and Client Council (PCC) Board Meeting in 2013, after which, the PCC agreed to investigate the experience of people living with ME.

Service users told us:

- There is no specialist service available;
- Misdiagnosis is common and other conditions e.g. cancer can go undiagnosed;
- Condition management programmes<sup>1</sup> can aggravate symptoms in those with severe symptoms;
- There needs to be a secondary care consultant in Northern Ireland; and
- GPs need to be given formal training in ME/CFS.

## We Did



- Feb 2015: The PCC, alongside charities, facilitated opportunities for discussion and debate on the main service gaps, including organising the #invisibleME Symposium in Belfast.
- July 2016: Using evidence on the lived experience of ME (gathered through PCC service user groups and conferences, in partnership with service users and carers), the PCC asked healthcare decision makers in Northern Ireland to prioritise improving diagnosis, providing adequate medical staffing and reviewing condition management programmes.



## What Happened



- 2018: HSCB 2017/18 Commissioning Plan confirmed commitment to develop a medically led regional diagnostic service for patients with ME and CFS.
- 2018: NICE agreed to review their guidance on ME diagnosis and management.
- 2018: Agreement has now been reached to appoint a part time secondary care medical consultant to support ME patients.
- The PCC is continuing to work in partnership with the Commissioner, service users and the appointed consultant to develop this service.

<sup>1</sup> A 12-week, voluntary programme delivered by healthcare professionals that aims to help people better understand and manage their health symptoms and return to a healthy lifestyle. These programmes can include an exercise element which service users feel can aggravate symptoms.

# Recurrent Miscarriage

Patient and Client Council  
Your voice in health and social care

Miscarriage affects around one in four pregnancies. A miscarriage is when a baby (or fetus or embryo) dies in the uterus during pregnancy. This applies up to 23 weeks and 6 days, and any loss from 24 weeks is called a stillbirth.

## You Said



In March 2014 the Patient and Client Council (PCC) was approached by women who had recently experienced miscarriage and wanted issues about their experience raised and addressed.

Women told us they would like the following made available within Northern Ireland (NI) for those who have had recurrent miscarriages:

- A review of existing services to ensure they meet patients' needs;
- A consultant who specialises in recurrent miscarriage;
- A dedicated recurrent miscarriage clinic with access to bereavement services and where a range of specialist tests could be carried out; and
- Timely access to a specialist counselling service in NI.

## We Did



- June 2014: PCC met with a group of women to understand their experience of miscarriage.
- April 2015: PCC established a Pregnancy Loss Steering Group (PLSG) which supported women and their families to meet with commissioners and clinicians to share their experience and recommendations for change.
- 2015: A scoping exercise was conducted to establish current service provision in NI.
- October 2015: A PCC event was held, bringing together commissioners, service providers and families who had experienced recurrent miscarriages, to discuss how services could be improved.
- September 2016: PCC gave a briefing to the NI Assembly Health Committee, highlighting the need for specialist recurrent miscarriage services and psychological help for those who need it.

## What Happened



### Raising Awareness

- 2015: The PCC and PLSG worked with the Miscarriage Association on early pregnancy loss literature. Posters and booklets were printed and distributed across NI.
- 2016: The PLSG supported by the PCC helped write and design a regional early pregnancy loss information leaflet for service users which was distributed across all HSC Trusts.
- 2016: The Miscarriage Association hosted a GP training session and information session for midwives.

### Training

- 2016: Early pregnancy bereavement awareness training now conducted across all Trusts.

### Service Development

- 2015: PCC staff and the PLSG, worked with statutory bodies to develop new pathways.
- 2017: RQIA recommended that each Trust has specialist perinatal mental health support services with psychological input.

# Chronic Pain

Chronic or persistent pain is defined as pain that carries on for longer than 12 weeks despite medication or treatment.

## You Said



In 2013, more than 2,500 people experiencing long-term pain took part in a Patient and Client Council (PCC) study to describe how pain affects their lives and to share their views on the treatment and care they were receiving. The findings of this study showed that:

- Getting a diagnosis is very important in helping people to accept and manage their pain as a long-term condition. However, getting a final diagnosis can prove difficult.
- Some participants felt let down and frustrated with the lack of support or recognition from their GP or consultant; they often felt like they were not believed, respected or taken seriously by healthcare professionals when discussing their pain.

Study participants wanted to see the following happen:

- Recognition of long-term pain as a condition in its own right;
- Integration of long-term pain management approaches across care settings and pathways;
- Development of training and information leaflets on chronic pain

for healthcare professionals, service users and carers;

- Provision of a range of person centred pain management care pathways for patients, including supported self-management; and
- Review of the use of mainstream alternative therapies in pain management.

## We Did



- 2015: The PCC has been a key partner in the Regional Pain Forum for Northern Ireland, an initiative set up by the Public Health Agency. As part of this service improvement exercise, the PCC has led in the development of a Service User and Carer Reference Group to facilitate co-design.
- 2015: The Regional Pain Forum actively developed plans for increasing access to community-based self-management programmes, improving information, enhancing training and service delivery in primary care and redesigning pain services in secondary care services.



## What Happened

- 2015: Chronic pain is now recognised as a long term condition and a regional strategy for chronic pain is being considered.
- 2016: Medical students are now trained in long-term pain management.
- 2016: Online pain management training module has been developed for pharmacists.
- 2016/17: Pain management made a priority area for Integrated Care Partnerships.
- June 2017: Service users from the NI Pain Forum took part in a hackathon #hackthepain which resulted in the inclusion of a 'Managing Your Pain' page on the MyNI website (<https://www.myNI.life/pain-management>), which provides online information about supported self-management.