

Making the visible the invisible on headache pain: sharing successful experiences across Europe

24th January 2018

Purpose

The Migraine Trust

Our vision

- A world free from the stigma and suffering of migraine

Support

- Evidence-based information
- Advocacy support service for people with migraine and their families
- Resources for professionals

Campaigning

- Forefront of campaigning and policy development
- Go-to organisation
- Bring together patients, health professionals and key stakeholders

Research

- Fund and promote research
- Migraine Trust International Symposium

Migraine – what is it?

“Migraine is an inherited tendency to have headaches with sensory disturbance. It’s an instability in the way the brain deals with incoming sensory information and that instability can become influenced by physiological changes like sleep, exercise and hunger.”

The challenge

In the UK:

- Nationally **recorded data** for headache and migraine is **not robust** enough to demonstrate the financial and non-financial impact
- **No national prevalence data** for headache disorders
- Headache disorders, and neurology more generally, are **not a national health priority** within the NHS
- There is **no national or regional leadership** to coordinate and facilitate change and improvement

As a result headache disorders are often:

- **poorly recognised, prevented, treated and managed** by sufferers and health professionals.
- people with headache disorders have **lower quality of everyday life** than the average population.

What would we like to achieve?

- Uniting the headache community and driving forward services and outcome improvements.
- People with headache disorders can successfully manage everyday life and work.

What we will do over the next 10 years

We will bring together people, neurologists, nurses, GPs, pharmacists and charities together to :

- Determine a strategy for improving services and outcomes.
 - Set up and deliver a sustainable programme of work to implement the strategy and ensure that headache remains a priority for the relevant agencies
- Ensure that people living with the condition are at the heart of this work that
 - Their priorities are the benchmark for developing high quality services.
- Work as a community in collaboration with the parliaments and NHS's of the devolved nations.
- Produce, collect and analyses data and intelligence to drive up standards of care.
- Measure impact.

Initial work

Initial meetings have concluded that any work we do must show:

- Improved patient reported outcomes and improved experience of care
- Improved preventative care / reduction of emergency attendances care
- Increase in optimal treatment / reduction of medication overuse headache
- Increased practitioner knowledge/ reduction in inappropriate investigations
- Increased appropriate referrals/ reduction in inappropriate referrals
- Increased access to specialist advice to direct management/ reduction in avoidable hospital admissions
- Increase in accurate diagnosis or primary headache disorders with classification as part of the diagnosis

A person with migraine will be able to:

- Act on consistent messages from across "the system"
- Optimally use medication and other treatments

Access:

- tailored information and education that enables me to understand my condition
- the most effective and safest treatment that I need
- appropriate specialist support when I need to
- opportunities to participate in research

What this 10 year project will achieve

What will be different?

- People with headache disorders can successfully manage everyday life and work

Outcomes in more detail:

Health

- Reduction of medication overuse headache

Behaviour

- Improved appropriate use of hospital and GP services for headache disorders
- Improved rates of accurate headache disorder diagnosis by health professionals
- Increased access to effective treatment of headache disorders
- Greater unity of the headache community
- Increased ability of people with headache disorders to prevent attacks
- Increased ability of people with headache disorders to manage attacks

What this 10 year project will achieve



Attitude and perception

- Improved national/health system-wide recognition and understanding of headache disorders

Service provision

- Reduction in unwarranted variation in services/outcomes/experience
- Increased access to optimal services and support
- Reduction of waste within the system
- Increased positive health outcomes
- Improved experience of the health system for people with headache disorders

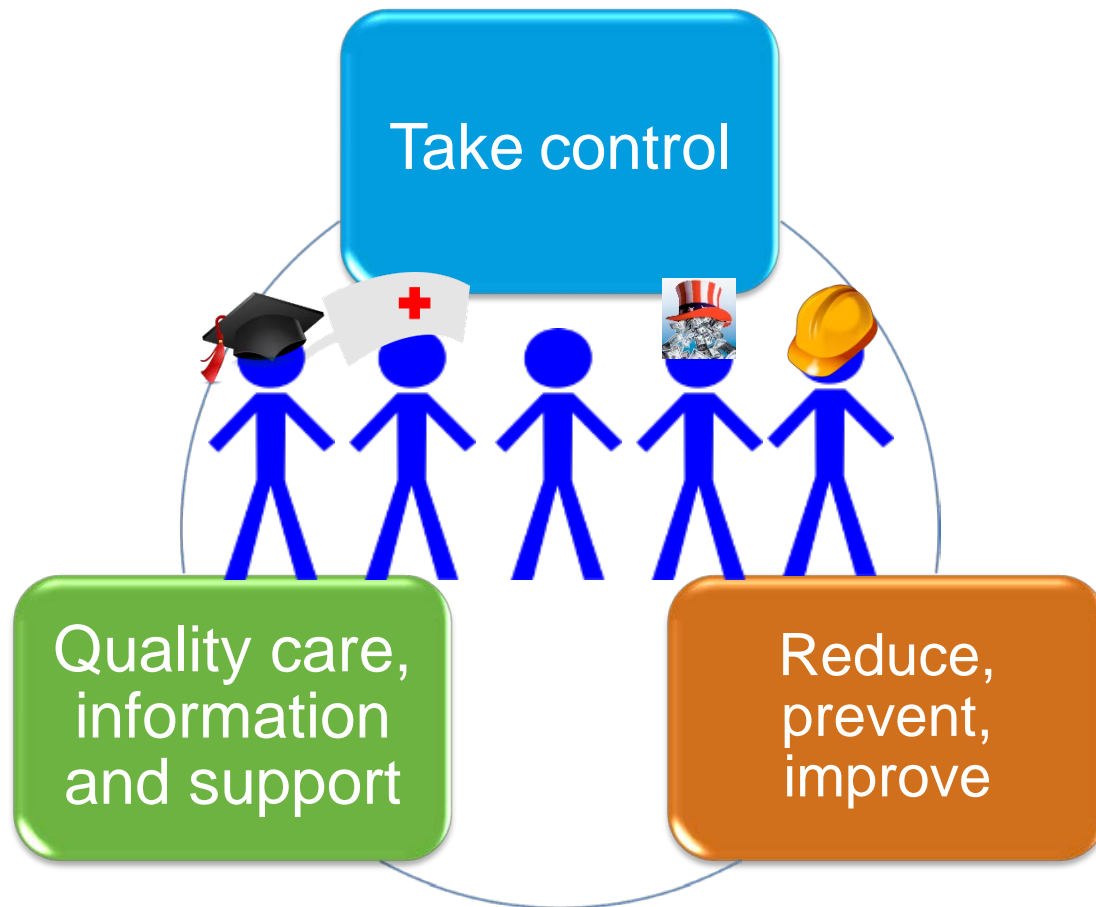
Prioritisation

- Increased engagement of CCGs, health boards and public health

Data

- Data has been used nationally and locally to improve standards of care

Aspirations



Thank you
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