

Headache and facial pain pathway: A summary of the patient focus group discussions facilitated by The Migraine Trust

Background

In July 2021, The Migraine Trust facilitated two focus groups with people affected by migraine to review the draft optimum clinical pathway for headache and facial pain. Rob Music and Gemma Jolly from The Migraine Trust facilitated the sessions alongside Dr Brendan Davies and Anne Marie Logan, headache specialists and members of the optimum clinical pathway steering group. Representatives from the Neurological Alliance and NNAG also support sessions.

Who took part?

11 people with migraine and/or headache disorder took part in the focus groups which were held as two online sessions.

What happens next?

The discussions and feedback recorded below will be used by the optimum clinical pathway steering group as they develop the final pathway for headache and facial pain.

The organisations involved will use the information to help inform their wider work.

	Focus Group 1	Focus Group 2	Direct Actions
Section 1: Diagnosis	<p>Information from the GP</p> <ul style="list-style-type: none"> • Felt let down by the GP • Lack of information and guidance given - it was left to the individual to google and get information • Mis information about the use of pain killers and inappropriate medication prescribed • GPs aren't taking migraine seriously • Feels like you are being a nuisance asking for help • Proper support is needed throughout to identify what works and what doesn't • Patients had to research and pay privately for better care - examples given were The National Migraine Centre and Acupuncture • Those who accessed a good neurologist/ headache specialist reported a good experience and appropriate information/treatment • Lack of information and use of headache diaries in primary care • The lack of standardisation and consistency is an issue • Poor information about treatments/medications provided and expectation management • It feels like you are bouncing around the system <p>Holistic support</p> <ul style="list-style-type: none"> • Support hasn't been offered to friends and family but it would be useful • Didn't feel the "whole person" was treated 	<p>Information from the GP</p> <ul style="list-style-type: none"> • GP lack of knowledge and awareness is a big issue that was raised throughout the discussion • Reports of a lack of information provided including poor use of headache diaries in primary care • Patients are providing information to GPs on treatments • Poor expectation management for treatments • Information from the National Migraine Centre helped to move things along • Prescriptions are giving but there's a lack of information on what outcomes to expect • Signposting would be helpful even if you have had a diagnosis for a long time • GPEducation and awareness must support this pathway <p>Referrals</p> <ul style="list-style-type: none"> • Is there a role for online referral tools? • Knowing there are things that would help but you can't get to them is a huge challenge <p>Triage</p> <ul style="list-style-type: none"> • Will GPs actually engage with the triage system? • There's a risk this could add barriers for getting the care that is needed <p>Incentivising GPs</p> <ul style="list-style-type: none"> • Some kind of mandatory funding or incentive scheme is needed to improve care in headache and get GPs interested 	<p><i>Pathway Group:</i></p> <ul style="list-style-type: none"> - Include timeframes and targets at each point along the pathway - Is there a quality outcome linked to information provision (tied into individualised care plan?) - Consider the use of ID migraine as a diagnostic tool for GPs <p><i>Migraine Trust/BASH:</i></p> <ul style="list-style-type: none"> - Information leaflets on treatments and what to expect to empower patients

<p>Section 2: Treatment</p>	<p>Mental health:</p> <ul style="list-style-type: none"> • All participants reported a lack of mental health support and recognition. Even when this has been self reported on waiting list forms its not being followed up • Suicide related question asked as part of a clinical trial but nothing has ever been touched on since <p>Self management and holistic care:</p> <ul style="list-style-type: none"> • Migraine care focuses a lot on the drugs but not the whole person - this differs really to diabetes care • The missing link is the connection between self-management and the health care professional - this needs to be a shared responsibility • Self management should be recorded and reviewed in partnership with the health professional <p>Follow up review:</p> <ul style="list-style-type: none"> • Asthma care involves a 20 minute annual review - could this model be used for migraine as a bring between seeing GP & neurologist - it would also be space to consider lifestyle and other areas <p>Remote consultations:</p> <ul style="list-style-type: none"> • Zoom reported as preferable to telephone calls • Positive reports of receiving the appointment quicker this way 	<p>Care plans and follow up reviews:</p> <ul style="list-style-type: none"> • Individualised care plans important - is this appropriate for the GP or does it need to be a migraine specialist in primary care? • quality standards/outcmes around making sure people don't get lost once in the pathway e.g. to avoid prescribe and forget <p>Medication management:</p> <ul style="list-style-type: none"> • Feels like you are a a "guinea pig" trying many types of medication without having expectations managed • There is a need for clearer information on how many medications is enough before being referred on. • Difficulties receiving referrals and a lack of clarity about how many treatment options had to be tried first (in one example 8 were tried before referral was made) • Treatments need to be reviewed with regular follow up • Pharmacist has a role here <p>Remote consultations</p> <ul style="list-style-type: none"> • Virtual consultations ok but for new patients and when needed face to face is important • Remote is better than nothing • A text alert could be used to invite you for an annual review 	<p><i>Pathway Group:</i></p> <ul style="list-style-type: none"> - Address what happens when you are in the pathway not just how you get to each point - Is there a quality outcome linked to review of treatment and care making use of digital support and can this be included in the pathway? - Address appropriate use of virtual/remote consultations in the pathway - Pathway to emphasise appropriate mental health support - Pathway to address what is actually meant by self management/holistic care. There needs to be an emphasis on this as part of the process of care.
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<p>Section 3: Barriers and recommen dations</p>	<p>Workforce Competencies:</p> <ul style="list-style-type: none"> • GP lack of awareness is a big issue. It puts a big onus on the individual to research and push for the right care <p>Peer support:</p> <ul style="list-style-type: none"> • Chat forums to communicate with other people would be very helpful <p>Self management</p> <ul style="list-style-type: none"> • The connection between self management and clinical input needs to be clearer. • The language is very important • Holistic is talking about lifestyle, exercise, diet and consider the whole person - not generic advice • For now people only talk about the migraine and the drugs • The impact on short term sickness absence is an important factor to consider 	<p>Self management:</p> <ul style="list-style-type: none"> • Self-management takes a lot of time and effort to work out what to do. People often left to do it on their own. Feels very lonely. The onus is on the individual and it can become overwhelming and exhausting. No-one follows up to see how you're managing. • Self management needs to be a partnership with your health professional which includes follow up and clinical input • Self-management can be hard to balance e.g. MOH and knowing when to take medication to stop migraine vs not taking it due to risk of MOH • Inappropriate self-management should be positively framed with appropriate techniques and treatments. MOH is often demonised. For some people they've done everything they've been asked and they still experience really bad migraine. • Should the pathway include information or links on triggers? <p>Peer support:</p> <ul style="list-style-type: none"> • Need for more support for people with migraine. Could they be organised/encouraged. Is there a way to harness social media to organise events/ provide online support? <p>Workforce competencies:</p> <ul style="list-style-type: none"> • There should be a basic competency in managing the most common neurological health condition • Nurse led service and ICPs could be helpful - could every CCG have this as a point of contact • Training and awareness for GPs is needed alongside pathways • New CGRP treatments provide an opportunity to upskill health professionals • Pharmacy should be better utilised 	<p>Pathway Group:</p> <ul style="list-style-type: none"> - Ensure self management points are addressed on the pathway and the wording is appropriate - <p>BASH/Migraine Trust:</p> <ul style="list-style-type: none"> - Explore training opportunities for health professionals alongside pathway <p>Migraine Trust:</p> <ul style="list-style-type: none"> - Involve people with migraine in plans underway to develop peer support mechanisms for the community - Share detail of future work on health economic argument when ready.
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