What people affected by migraine are telling us needs to change:
a discussion paper
About our ‘State of the Migraine Nation’ programme

For the past 54 years, The Migraine Trust has worked to make sure that people affected by migraine are heard. We’re extremely proud of the work we’ve done to advance migraine research and understanding, and the progress our community has made. But we also know we still have a long way to go to make sure that every person with migraine has the best life chances possible.

That’s why we’ve started work on a ‘State of the Migraine Nation’ report. Our report will map the progress our community has made, identify the emerging issues that matter most to people with migraine today, and seek to draw our community together around a series of campaigning priorities for the future. We hope the report will be of interest to policy makers, employers, NHS leaders, and the whole migraine community.

The report will be launched at our 18th Migraine Trust International Symposium (MTIS) Public Day in London on 13 September 2020 and will form the basis of our organisation’s campaigning agenda for the next decade. To inform the report’s recommendations, between now and then we will be carrying forward a varied programme of evidence-gathering and engagement.

We are keen to involve people affected by migraine in every stage of the development of this report. If you are interested in being more involved, please consider joining our ‘informal sounding board’ of experts and people affected by migraine. To learn more about what this entails or to join, visit our project webpage here or email policy@migrainetrust.org
About this discussion paper

This is the first of a number of discussion papers we will be developing as part of our ‘State of the Migraine Nation’ programme. It focuses on the views and ideas of people affected by migraine and presents some new and compelling evidence about what living with migraine is really like today.

We have gathered the experiences and insights of people affected by migraine in the following ways:

1. **Our migraine community survey** – this was the largest survey of the UK’s migraine population that we’ve ever done in our nearly 55-year history. It was completed by over 1,800 people affected by migraine during October and November 2019

2. **A series of semi-structured phone interviews** with 18 members of our Volunteer Forum conducted during August and September 2019

3. **A workshop held with the Chronic Headache and Migraine Patient Support Group (CHAMPS) in Manchester** on 15 October 2019. The workshop was attended by over 35 people affected by migraine

4. **Volunteer Forum meeting workshop** held with 11 members of our Volunteer Forum on 26 October 2019

This discussion paper was also reviewed by members of our ‘informal sounding board’ of people affected by migraine and other experts.
Four major themes

We think four major themes have so far emerged from our consultation so far with people affected by migraine about how migraine has impacted their life and what they would like to see change. These are:

1. Diagnosis
2. Care and treatment
3. The wider impact of migraine
4. Public attitudes and awareness raising

Under each theme, key questions are emerging that we need further help in answering. We will use these answers to feed into our final ‘State of the Migraine Nation’ report.

You can feedback to us by emailing policy@migrainetrust.org or tweeting us with the hashtag #MigraineNation. We are incredibly grateful for any and all help you can give us.
**Theme 1: Diagnosis**

A major theme to emerge from our consultation with people affected by migraine is diagnosis. Despite how prevalent migraine is, we heard that receiving a correct diagnosis can be time-consuming, stressful, and difficult for many – if they receive a formal diagnosis at all.

Our migraine community survey shows that more than half of survey respondents experienced symptoms for more than a year before seeking help from their GP, only around a third were diagnosed on their first visit, and 29% had to see a health professional five or more times before they received a correct diagnosis.

The situation appears to be even more concerning for people from Black, Asian, and minority ethnic (BAME) backgrounds. Nearly three quarters (73%) of BAME survey respondents experienced symptoms for more than a year before seeking help from their GP, only 20% were diagnosed on their first visit, and 41% had to see a health professional five or more times before they received a correct diagnosis.

These concerning survey findings were reflected in our face-to-face conversations with people affected by migraine. For example, some members of our Volunteer Forum were never diagnosed, several were misdiagnosed, one waited over 20 years for a correct diagnosis, and several others saw a long list of health professionals in error (including opticians, physios, and dentists) for their migraine symptoms before they were correctly diagnosed.

As one Volunteer Forum member said:

“I accept that figuring out what works for my migraine is going to be a long and sometimes lonely journey, but I don’t think my diagnosis should have been.”

Throughout our consultation, people affected by migraine have been clear that a timely and correct diagnosis has to be at the heart of what good care and treatment for people with migraine looks like.

**Questions**

1. What do you think are the key barriers standing in the way of people with migraine receiving a timely and accurate diagnosis?

2. If you had a good diagnosis experience, what do you think ‘went right’ for you?
Theme 2: Care and treatment

People affected by migraine are telling us that migraine care and treatment is falling well short of acceptable standards and that they are not being well supported to manage their migraine in the long term.

Less than one third of respondents to our migraine community survey are satisfied with their current care and treatment and only 15% believe that the NHS can manage migraine well. We heard that children and young people in particular are being let down.

At our two workshop events, we asked people affected by migraine to discuss some of the top issues they have faced throughout their NHS migraine care and support journey.

While many different issues were mentioned, ranging from mental health support to lack of access to medications, there were two issues that both groups prioritised as particularly important:

1. There is a lack of GP knowledge about migraine

We heard that many people with migraine want to – and feel that they should be able to – manage their migraine well in primary care in partnership with their GP. However, due to a lack of GP knowledge about migraine, this isn’t always possible.

In particular they mentioned that GPs often don’t understand the ‘fundamentals’ of migraine, including medication overuse headache, the trial and error nature of migraine management, the balancing act between the positive effect of a particular medication and the adverse side-effects of that medication, and the higher prescribing levels necessary for the ‘migraine brain’.

This means that even if your GP can recognise migraine and feels confident to diagnose you, they may often still struggle to manage you effectively in the long term. As a consequence, people with migraine have told us that they feel pushed out of primary care unnecessarily and compelled to seek help from a specialist.
As one person said during a phone interview:

“A big problem for me was medication overuse headache. No one ever told me about it until I finally saw a neurologist who diagnosed me. I did the detox treatment and it was effective; this has made a massive difference. I now can take a triptan once per week and that is it.”

2. It is too difficult to access specialist care

Workshop participants told us that they encountered long waiting times to see a specialist, with many saying they had to wait over a year to see a specialist or have been completely unable to access specialist support or treatment, such as Botox injections.

This is supported by the finding from our migraine community survey that 28% of respondents have had to pay privately to see a health professional about their migraine in the last five years, with most paying to see a neurologist who specialises in headache.

As one person said during a phone interview:

“The waiting list to see a neurologist was so long that I went privately and then paid for all of the tests privately.”

Questions

1. Do you agree with our workshop participants that these are some of the most pressing issues that people with migraine face when they receive care and treatment? If not, what do you think we’re missing?

2. What do you think are some of the solutions to the problems identified above?

3. Do you think pharmacists play an important role in helping people manage migraine?
Theme 3: The impact of migraine

People affected by migraine told us that the impact migraine has on their lives has been considerable, touching on education, work, home and family life (including the decision to have children), and mental health and wellbeing.

They mentioned that migraine means you may stop investing in things fully, you may find it difficult to plan in advance, and you may feel that you cannot be relied on. This may lead to reduced opportunities in all aspects of life. For many of our workshop participants and Volunteer Forum members, it was difficult for them to put into words just how all encompassing their migraine has been for them.

Findings from our migraine community survey can help us better understand the scale of the impact that migraine has. When we asked respondents to tell us how migraine has impacted their life, this is what they told us:

<table>
<thead>
<tr>
<th>People with migraine were asked to what extent they agreed or disagreed about the following statements – with 1 being definitely disagree and 10 being definitely agree</th>
<th>AVERAGE SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Migraine has had a significant impact on my life overall</td>
<td>8.8</td>
</tr>
<tr>
<td>Migraine has had a significant impact on my social life</td>
<td>8.3</td>
</tr>
<tr>
<td>Migraine has had a significant impact on my career</td>
<td>7.6</td>
</tr>
<tr>
<td>Migraine has had a significant impact on my mental health</td>
<td>7.3</td>
</tr>
<tr>
<td>Migraine has had a significant impact on my relationship with my partner / spouse</td>
<td>6.8</td>
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</tbody>
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47% of respondents consider themselves to have a disability as defined by the Equality Act 2010 because of their migraine.

These findings show how impactful migraine can be across people’s lives.
Out of all of these areas, we wanted to know if there was one specific area that people with migraine most wanted to see better understood, recognised, or addressed. We asked participants at our Manchester workshop to consider all of these ‘impact areas’ and then vote on the top issue that they most wanted to highlight. They voted for the impact that migraine has had for them at work and on their careers more broadly.

Describing that impact, they wrote:

“The impact of migraine at work cannot be overstated and includes: having to run to catch up with colleagues, the fear of losing your job, reduced productivity (and importantly the perception of reduced productivity), being perceived as an unreliable colleague, the loss of income and opportunities, the loss of autonomy at work, and having to take time off work.”

People with migraine told us that, while improvements in care and treatment would absolutely help improve their lives in the long-term, there also needs to be improvement in how people with migraine are supported in the workplace.

Questions

1. What do you find most interesting or surprising about the survey findings about the impact of migraine?

2. What do you think most needs to change to support people with migraine to stay and thrive at work?
Theme 4: Public attitudes and awareness raising

Throughout our conversations about all three of those above themes (diagnosis, care and treatment, and wider impact), people affected by migraine kept coming back to this larger issue of a lack of awareness and understanding of migraine. Whether it’s a lack of understanding from their GP, their line manager, or ‘the public’ generally, people affected by migraine told us that they are exhausted from having to fight the many misconceptions about what living with migraine is really like.

We heard that we’ll only improve diagnosis rates, the care and treatment experience, and the detrimental impact that migraine can have if we raise awareness about migraine and change public, medical, and employer perceptions of the condition.

People affected by migraine told us that raising awareness of migraine is going to be an uphill climb. They said that migraine is often dismissed or trivialised in wider society, popular culture, and the media – if mentioned at all.

Respondents to our migraine community survey corroborated this sentiment, with 68% believing that migraine is represented inaccurately in the media and 66% saying they ‘rarely’ or ‘never’ see stories about migraine in the media.

Negative or unhelpful public attitudes – or what one Volunteer Forum member described as ‘persistent, low level stigma and confusion’ – about migraine contribute to the feeling of isolation and loneliness that so many of our workshop participants said they feel because of their condition.

We heard that being understood is very important. One member of our Volunteer Forum sums up a common sentiment amongst the people affected by migraine we spoke with when she said:

“The support aspect is key. When I finally spoke to a specialist nurse who ‘got it’ I was in tears for being recognised.”
Questions

1. What do you think the public most needs to know about migraine?
2. What do you think employers most need to know about migraine?
3. What do you think the NHS workforce most needs to know about migraine?
4. What do family and carers most need to know about migraine?
5. What one aspect of migraine, or key message, do you think should be at the centre of a migraine awareness raising campaign?

Next steps

We’ve produced this discussion paper to spark a wider conversation with people affected by migraine about their priorities for change in order to help us develop our ‘State of the Migraine Nation’ report and improve the lives of people affected by migraine.

We would be extremely grateful if you would answer the questions we pose throughout the paper by emailing policy@migrainetrust.org or tweeting us @MigraineTrust using the hashtag #MigraineNation.

We will use the answers you provide to continue to engage with people affected by migraine, the NHS workforce, policy makers, and researchers about the issues that matter most to the migraine community.

To help the discussion even further, we’ll be releasing a series of blogs on The Migraine Trust blogsite over the coming weeks and months. You can read them here.

We’ll also be releasing a series of evidence reviews about some of the issues this paper touches on beginning in March 2020. To ensure you are able to see the latest progress on this work, please subscribe to our monthly e-bulletin by clicking here.

Thank you very much in advance for your time and insights!
About The Migraine Trust

The Migraine Trust is the largest research and support charity for people affected by migraine in the UK. Our role is to fund and promote new research into migraine, provide day-to-day support for people affected by migraine, and campaign for change.

Since we were founded in 1965, we have funded over 130 medical research projects that have improved our understanding of migraine and encouraged new researchers into the field. We hold an international symposium every two years, bringing together the world’s leading experts on migraine and headache to share latest research findings and discuss current trends in treatment and prevention. The next Migraine Trust International Symposium (MTIS) will be in London on 10-13 September 2020.

We also provide evidence-based information and support on all aspects of migraine and help people with migraine experiencing difficulties at work, in education, or in accessing healthcare services via our website and our information and advocacy helplines. Every year over two million people visit our website and over 2,300 people receive support through our helplines.

We campaign for national policy change to improve the lives of people affected by migraine. We are currently developing a ‘State of the Migraine Nation’ report that aims to explore the challenges and opportunities facing the migraine community today and identify priorities for future change across the UK.

To learn more about the latest in migraine research and treatment, the support we provide, and how you can get involved in the work of our charity, please subscribe to our monthly e-bulletin by clicking here or visiting the homepage of our website at migrainetrust.org.