



Acknowledgements

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Foreword

By Rob Music, CEO of The Migraine Trust

This research lifts the lid on the severe impact migraine has on young people living with the condition, particularly in school, and highlights an urgent need for improved guidance, information and support for them, their families, and health and education professionals. We need to see a major and wide-ranging culture change that enables children and young people to talk about their migraine, be understood and be supported by both the health system and their schools.

Migraine affects one in ten children. This is around 1.2 million children in the UK and has implications for younger sufferers in terms of loss of learning, impact on exam performance, and the knock-on from this with potential future jobs. Even more so than with adults, this means that migraine can have a lasting effect on life, disrupting their future in their

formative years. We heard from children who said they feel they can't do what they want in life, while over half of parents/carers of affected children reported that their children were at home with migraine at least once a month and that support from their school has been insufficient.

*"I missed a lot of school last year because of my migraines and I couldn't do the things I enjoy such as football and dancing and that made me sad."
- Joel, who has migraine*

The Migraine Trust has produced new information and support for children and young people with migraine, their parents, carers, teachers and doctors, which is available at migrainetrust.org/migraine-in-children-and-young-people/. But we need to go further to ensure that local health services can meet the needs of children and young people with migraine; that primary care has the up-to-date information they need on paediatric migraine care; and schools and colleges recognise and support needs appropriately. The recommendations in this report will help services to come together and provide this essential care.

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Executive summary

Migraine is much more than a headache; it is a severe and painful long-term brain disorder. If someone has migraine they will have migraine attacks, which can be a whole-body experience.

While migraine has a significant impact on the lives of adults who live with it, its impact on children can be even more severe.

An estimated one in ten children are living with migraine.¹ This potentially limits their development and ability to take part in education, social activities, and other important parts of growing up. It can also be hard for children to understand and explain their pain, and there are fewer treatment options for them than there are for adults.

Common symptoms of a migraine attack can include head pain; problems with sight such as seeing flashing



lights; being very sensitive to light, sounds and smells; fatigue; and feeling sick and being sick. Four in 100 children are also affected by abdominal migraine, which triggers severe stomach pain.² However, different people get different symptoms. When someone has a migraine attack, they may not be able to function normally.

Based on a variety of workshops and surveys with children and young people who have migraine, parents and carers, and education professionals, this report highlights a clear need for better understanding of how migraine impacts children and for tailored information, guidance and support for children and young people of different ages who have migraine.

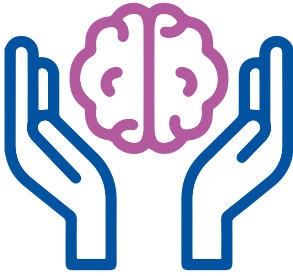
Key findings include:

- Children, particularly younger children, often need help in explaining their migraine and need to be included in discussions about their treatment.
- There needs to be better communication, where possible, between health services and schools/colleges.
- Older children often aren't prepared for living with migraine as an adult, as they may have to deal with a very different environment once living away from home. This can present a new range of migraine care triggers and barriers, such as finding the confidence to visit a doctor by themselves or needing to manage their migraine in a workplace.
- There is a strong desire to connect with other people going through migraine, from both children and young people and their parents/carers.
- There is a clear need for additional support for children and young people. When asked about how an organisation such as The Migraine Trust might support them, 53% of children and young people who responded to the survey said they wanted more online information; 39% wanted a "buddy system" to contact other people with migraine; 35% wanted a support group; 24% wanted a webchat, 24% wanted a helpline they could text, 20% wanted online events to learn about migraine, and 12% wanted a helpline they could email.
- 90% of children and young people responding to our survey said their migraine made it harder to do their schoolwork. 70% of parents/carers with a child living with migraine were concerned about the impact of it on their education.
- 76% of education professionals surveyed felt that their school did not have the information, resources and processes to help children in school with migraine. For example, school policies are often not geared towards helping children manage their migraine triggers and avoid being unnecessarily sent home. However as well as policy change, cultural change is required to ensure that children with migraine are understood in school.

¹ Barnes, N (2020) 'Migraine headache in children', British Medical Journal (BMJ) Best Practice. Available at: <https://bestpractice.bmj.com/topics/en-gb/678>

² Read here for more on abdominal migraine: migrainetrust.org/understand-migraine/types-of-migraine/abdominal-migraine/

Recommendations



Health services and mental health

- **The UK health departments should support new tailored information and guidance materials for children and young people.** These will help children and young people self-manage to an appropriate degree and interact with their family, with school staff and health professionals they see. The Migraine Trust could be an active partner in the development of these materials and draw on networks to ensure they reflect lived experience of young people and their carers.
- **ICSs in England and Health Boards in Scotland, Wales and Northern Ireland must include children and young people in reviews of local migraine needs,** and ensure they have services to meet those needs. In England, the [NHS RightCare Toolkit](#) should be used to support service improvements.
- **ICSs in England and Health Boards in Scotland, Wales and Northern Ireland must ensure there are strong links between migraine care and mental health services.** Mental health must also be a component of the healthcare pathway for children with migraine, as mental health issues and migraine are often co-morbid, with one leading to or worsening the other.
- **GPs and pharmacists should receive dedicated training on the management of migraine in children and young people.** The British Paediatric Neurology Association, Royal College of GPs, the National Pharmacy Association and other stakeholders will be critical to delivering this and seeing it adopted.
- **GPs should liaise with the child/young person's school** to ensure the school is able to provide appropriate support. Something as simple as a letter from the GP to the school will often help ensure their condition is understood and guidance is followed. General Practice Nurses could also liaise with the school to develop a care plan and review it.





School/college leadership

- **Clear government guidance and information for staff on migraine**, as part of general guidance on health and wellbeing. The aim of this is to strengthen awareness of migraine, ensure reasonable accommodation and ease the mental health burden children feel from not being understood. This could work with departments for education, public health bodies and local authority school services to develop and diffuse guidance.
- **Training modules on the management of migraine in children and young people** for those working in schools and colleges. This could include work with the School and Public Health Nurses Association, Health in Education Association, PSHE Association, National Association for Primary Education, Association of School and College Leaders, the Sixth Form Colleges Association, Association of Colleges, Colleges Wales & Scotland, Further Education Northern Ireland, Independent Schools Association, and other relevant stakeholders on delivering it and seeing it adopted.
- **Guidance and case studies should be provided to education settings on ensuring that medical guidance is taken into account** and reasonable adjustments are made.



Support for families

- **Health systems and schools/colleges should provide guidance and information for parents/carers.** In collaboration with The Migraine Trust, health and education services should provide materials that will cover migraine, its management, how to talk about migraine and how parents/carers can work with schools and healthcare professionals. Separate guidance could also be developed to help siblings of children with migraine to contribute to support.
- **Schools and boards of governors should engage with parents/carers of affected children. Information could also be provided to parents/carers on how best to work with school management and governors, through schools or organisations such as Parentkind.**
- **Local health systems and schools should support the development of support groups** for the parents/carers of children and young people with migraine.



Methodology

This report explores how migraine impacts children and young people; what resources are already available in the healthcare system and education institutions; present gaps in information and support; and current issues in processes and policies that hinder the management of migraine in children.

It is based on a variety of focus groups, interviews and surveys including:

- A roundtable discussion with 11 key people in health and education who are working to help children impacted by migraine in the UK.
- Two workshops for parents/carers of children with migraine. One explored their children's experiences of migraine healthcare, and the second explored the wider experience of living with migraine on their child and family, and their coping strategies.
- Two workshops for young adults (aged 18-21) with migraine who have recently experienced migraine healthcare as children. One explored their experience of migraine healthcare as a child, and the second explored the wider experience of living with migraine and what they think would have helped them with their migraine as they grew up.
- Three online surveys, one for children with migraine (61 participants), one for parents and carers of children with migraine (139 participants), and another for people working in schools (64 participants).

These were supplemented by desk research which looked at how children and young people are segmented by media and organisations which target them; how other health charities communicate to and support children; and what information about migraine and wellbeing is available in the school curriculum.

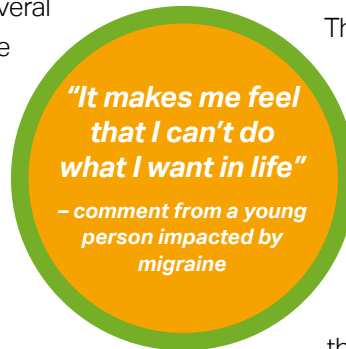


Key findings

How migraine impacts children and young people

The focus groups and surveys highlighted several common themes about the nature of migraine among children and young people:

- Children, particularly younger children, often need help in explaining their migraine or are not always believed.
- Older children often aren't prepared for living with migraine as an adult, as they may have to deal with a very different environment once living away from home. This can present a new range of migraine care triggers and barriers, such as finding the confidence to visit a doctor by themselves or needing to manage their migraine in a workplace.
- There is a strong desire to connect with other people going through this, from both children and young people and their parents/carers. Young people experiencing migraine reported feeling isolated, alone and 'different', which made it harder to live with.



Institute for Health and Care Excellence (NICE) has estimated the prevalence of migraine among women in the UK to be around 24% of the adult population.⁴

There is also a strong relationship between migraine and mental health. Migraine is a significant cause of stress and anxiety for children impacted by it. Stress and anxiety are also a significant migraine trigger, including for children dealing with difficult life circumstances or feeling stressed about exams.^{5,6} 72% of our survey respondents said that their migraine made them feel worried.

Age when had first migraine attack	%
Under 5	26
6-7	18
8-9	21
10-11	13
12-13	16
14-15	5
16-18	0

Sample: 61 children and young people with migraine

Our survey of children with migraine found that a majority (66%) of respondents reported experiencing an attack by the time they were the age of 9, and about a quarter (26%) had even experienced one by the age of 5. 80% experienced an attack at least once a month, and 26% experienced them 3-5 times a month.

61% of our sample identified as female, in line with the disproportionate impact migraine is reported to have on women in general. Migraine is between two and three times more common among women than among men, likely to be a result of hormonal factors, genetic differences and potential under-reporting among men.³ The National

How often do they experience a migraine attack?	%
Less than once a month	20
Once a month	16
Twice a month	13
3-5 times a month	26
6-7 times a month	3
8 or more times a month	21

Sample: 61 children and young people with migraine

3 European Migraine and Headache Alliance. (2021). 'Migraine in the EU: Bringing women out of the shadows'. Available at: <https://www.emhalliance.org/wpcontent/uploads/Women-M-Policy-Paper-FINAL23MARCH.pdf>

4 The Migraine Trust (2021) 'State of the Migraine Nation, Dismissed for too long: Recommendations to improve migraine care in the UK'. Available at: https://migrainetrust.org/wp-content/uploads/2021/09/Dismissed-for-too-long_Recommendations-to-improve-migraine-care-in-the-UK.pdf

5 Maleki, N., Becerra, L. & Borsook, D. (2012) 'Migraine: Maladaptive Brain Responses to Stress'. [Online] 52 (Suppl 2), 102-106. Available from: doi:10.1111/j.1526-4610.2012.02241.x

6 The Cleveland Clinic, 'Migraines in Children and Adolescents'. Last updated April 2022. Available at: <https://my.clevelandclinic.org/health/diseases/9637-migraines-in-children-and-adolescents>

Respondents were also asked about their approaches to managing migraine:

- To try make their migraine attacks better, 84% try to sleep, 82% take medication, 69% lie down, and 45% put something cold on their head.
- 36% have a paper headache diary and a further 11% use an app or a digital document. However, 28% decided not to use one and 25% had never heard of headache diaries at all.
- 38% sometimes talk to their friends about their migraine, though 34% only do so rarely and 25% never do.

If they would like help from the charity, how would they like it?	%
Information on The Migraine Trust website	53
A buddy system to contact other people with migraine	39
A support group	35
Helpline that I can text	24
Webchat on The Migraine Trust website	24
Online events to learn about migraine	20
Helpline that I can email	12
Helpline that I can phone	10

Sample: 61 children and young people with migraine

Comments children and young people shared with us about the reality of living with migraine emphasise the wide-ranging impact of it on their lives and the lack of control they feel over it.

"I want to make it stop, why won't it stop?"
 - comment from a young person impacted by migraine

Healthcare

Of the children and young people responding to our survey, 33% felt the treatment of their migraine was poor, 30% said fair, 23% said good and 8% said very good. None described it as excellent.

Communication and decision-making. Our findings suggest that it is important that children are included in discussions about their treatment and that it is not just bilateral between parents/carers and their doctor. Children need to be talked to, not at, about their migraine. The Royal College of Paediatrics and Child Health (RCPCH) has previously found that children/young people say that good communication with health services means the following to them:⁷

- "It needs to be easy to tell [doctors] what I need or what I think"
- "It would be good if we could email or message [doctors] our questions before the appointment in case we forget or aren't brave enough to ask"
- "I want to feel that I understand my doctor and what he is saying, so that I don't have to ask mum afterwards"
- "Communication is about building up trust, it's nice when the doctor knows I like cadets and asks me at the start. It makes me feel comfortable"

⁷ Royal College of Paediatrics and Child Health (2018) 'What does the domain "communication" mean to children and young people'. Available at: https://www.rcpch.ac.uk/sites/default/files/2019-02/cyp_progress_domain_communication.pdf



Research has also found that children want to be involved in decisions about their health and wellbeing, and that children often feel ignored or left out by the adults in these interactions. Children may not always understand why they are coming to a service or may struggle with terminology. Crucially, research also suggests that children who feel adequately involved in conversations about their health are more likely to adhere to treatments, making interventions more effective. However, evidence also suggests that more needs to be done to meaningfully engage children and that child-centred practice is not well-defined.⁸

Migraine and mental health. Migraine is often co-morbid with mental ill-health. For example migraine can lead to anxiety and anxiety can lead to migraine, so there is a complex interplay between the two conditions. It is important that communications to children about their migraine and mental health help them to manage it and not take over their life, or detract from all the good things in it. Often this means giving children with migraine information about pacing themselves and targeting help at preventing children and young people from becoming stressed and anxious about their migraine in the first place. This approach can be encouraged in health services, both in schools and in guidance for parents/ carers on how to approach these conversations.

Recognition. Most children with migraine don't need to see a specialist. They just need good care, support and information from their GP and in school. On top of the more general problems that exist with understanding of and training about migraine in primary care, GPs and community pharmacists often may not understand migraine in children in particular and how to help them. For example, they may not recognise it as a condition that children can get.

Medication. It is important that parents/carers, schools and GPs are aware of medication overuse headache and how it is caused.⁹ However, our research also suggests that GPs are reluctant to prescribe more appropriate preventive medications to children, even if a child with migraine would benefit from them.



⁸ O'Reilly, M. & Karim, K. (2016). 'How can local research improve care and communication with children?' Poster presented at the Local Leicestershire Partnership NHS Trust Research Fair, Leicester.

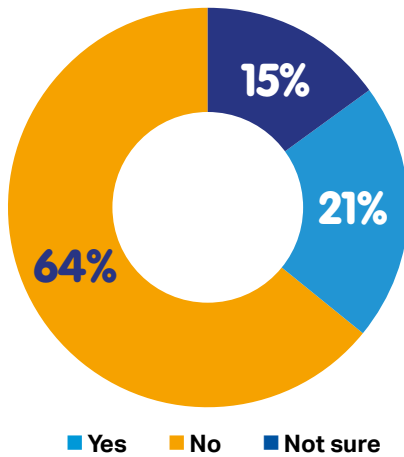
O'Reilly, M., & Karim, K. (2017). 'Communicating with children: what does the research show.' Paper presented at the Local Leicestershire Partnership NHS Trust Research Fair, Leicester.

⁹ Information on the background of medication overuse headache and treatments can be found here: <https://migrainetrust.org/understand-migraine/types-of-migraine/medication-overuse-headache/>

Schools

90% of children and young people responding to our survey said their migraine made it harder to do their schoolwork. However, when asked if they think that their school has the information about migraine to help them manage it at school, 64% said no. When asked if they have ever been taught about migraine at school, 97% said that they hadn't.

Do you think your school has the information about migraine to help you manage it at school?



Sample: 61 children and young people with migraine

There is clearly a need for more information for teachers and staff to understand migraine and its impacts, to enable them to make necessary adjustments to enable children and young people who live with migraine to make the most out of their education.

We also surveyed 64 people working in education settings. Those who responded tended to be school nurses, teachers or teaching assistants. When asked how often a child where they work tells them that they have a headache, 26% of the staff said several times a week, 33% said several times a day and 9% said once a day. When asked how often a child tells them that they are having a migraine attack, 16% said once a week, 14% said several times a week, 11% said once a month, 3% said once a day and 2% several times a day.

"I have had to be a very strong advocate for her in order to get her the medical support she needs, as well as get the school to understand and make reasonable adjustments."
 – Comment from a parent of a child with migraine

Despite this, 76% said they felt that their school did not have the information, resources and processes to help children in school with migraine.

In terms of what would help them to support a child in school who tells them that they have migraine or who displays symptoms of a migraine attack, 81% supported a process whereby a child diagnosed with migraine is given ongoing support by the school. 78% said they would value information about how to help a child manage their migraine, and 57% said they would value information about how to talk to children about it.

Health education in government guidance for schools and colleges

Health education is mandatory in state-funded primary and secondary schools in England. Department for Education (DfE) guidance suggests that schools must publish policies for this online and make them available to anyone free of charge. Schools are also advised to share examples of resources (for example, books and information leaflets) to help them engage and consult with parents. There is no

mention of headache or migraine in the relevant DfE publication, *Relationships Education, Relationships and Sex Education (RSE) and Health Education: Statutory guidance for governing bodies, proprietors, head teachers, principals, senior leadership teams, teachers*, although there is an emphasis at primary and secondary level on the importance of a healthy lifestyle.¹⁰ The Department for

Education also provides statutory guidance on physical health and mental wellbeing in primary and secondary schools, including physical health and fitness, diet and prevention, but does not cover specific conditions such as headache or migraine in detail.¹¹

"It affects more of you than your head"
 – comment from a young person impacted by migraine

Government guidance under the Children and Families Act 2014 stresses that pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education. Governing bodies must ensure that arrangements are in place in schools to support pupils at school with medical condition.¹² If migraine persists for more than 12 months, it can also be considered a disability under the Equality Act 2010, creating a particular duty for schools to make reasonable adjustments.^{13 14}

In Scotland, Scottish Government general guidance on health and wellbeing in schools does address lifestyle factors such as food and particularly emphasises mental health, but does not appear to address headache or migraine.¹⁵ The 2017 draft guidance for Scottish NHS boards, education authorities and schools on supporting children and young people with healthcare needs in schools briefly mentions headache, but in the context of guidance around parental permission on administering medication:¹⁶

- “If a child or young person suffers regularly from acute pain or symptoms, such as a headache, period pain or hayfever, parents may provide the school with non-prescribed medication alongside clear and appropriate instructions and consent for the medication to be (often via the completion of a standard form). Alternatively parents (or where appropriate the young person) may ask for the medication to be prescribed by a GP.”

- Some children and young people with the maturity and capacity to carry and self-manage their own non-prescribed medication and symptoms (for example, for period pain, occasional headaches, minor viral illnesses, coughs, sore throats or hayfever) should be allowed to do so.”

In Wales, 2017 government guidance on health and wellbeing for learners emphasised physical and mental health, reasonable accommodation and the need for local authorities to “make arrangements to promote cooperation between various bodies or persons, with a view to improving, among other things, the well-being of children in relation to their physical and mental health”. The document does not mention migraine or headache specifically, but did link to the former charity Migraine Action¹⁷ as one of a number of resources.¹⁸

In Northern Ireland, there is government guidance that helps schools to form their own medicines policies and procedures to ensure that pupils with medication needs receive appropriate care and support at school, though it does not mention specific conditions.¹⁹

¹⁰ Department for Education (2019) Introduction: ‘Relationships Education, Relationships and Sex Education (RSE) and Health Education’. Available at: <https://www.gov.uk/government/publications/relationships-education-relationships-and-sex-education-rse-and-health-education/physical-health-and-mental-wellbeing-primary-and-secondary>

¹¹ Department for Education (2021) ‘Statutory guidance: Physical health and mental wellbeing (Primary and secondary)’. Updated 13 September 2021. Available at: <https://www.gov.uk/government/publications/relationships-education-relationships-and-sex-education-rse-and-health-education/physical-health-and-mental-wellbeing-primary-and-secondary>

¹² Department for Education (2014) ‘Supporting pupils at school with medical conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England’, April 2014. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/306952/Statutory_guidance_on_supporting_pupils_at_school_with_medical_conditions.pdf

¹³ Department for Education (2014) ‘The Equality Act 2010 and schools: Departmental advice for school leaders, school staff, governing bodies and local authorities’, May 2014. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/315587/Equality_Act_Advice_Final.pdf

¹⁴ National Migraine Centre (2022) ‘Migraine: Advice to schools’. Available at: <https://www.nationalmigrainecentre.org.uk/migraine-and-headaches/migraine-and-headache-factsheets/migraine-advice-to-schools/>

¹⁵ Scottish Government, ‘Health & Wellbeing in Schools’. Available at: <https://www.gov.scot/policies/schools/wellbeing-in-schools/>

¹⁶ Scottish Government (2017) ‘Supporting children and young people with healthcare needs in schools: Guidance for NHS boards, education authorities and schools’. Available at: <https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2017/12/supporting-children-young-people-healthcare-needs-schools/documents/00529511-pdf/00529511-pdf/govscot%3Adocument/00529511.pdf>

¹⁷ Migraine Action merged into The Migraine Trust in 2019

¹⁸ Welsh Government (2017). ‘Supporting learners with healthcare needs’. Available at: <https://gov.wales/sites/default/files/publications/2018-12/supporting-learners-with-healthcare-needs.pdf>

¹⁹ Northern Ireland Department for Education, ‘Support for pupils with medication needs’. Available at: <https://www.education-ni.gov.uk/articles/support-pupils-medication-needs>

Awareness and school policies

There is an issue of lack of awareness and understanding of migraine in schools, particularly how it affects children and how schools can help them. School policies are not designed for a condition such as migraine and there are particular problems with children being unable to stay hydrated during the day, being made to play outside, or being able to go home if they have a migraine attack. This in turn adds to the stress and anxiety that they experience about their migraine, but also to the frustration that their parents and carers experience.

Support for families

Parents need support to help them to identify migraine, manage the impact of their child’s migraine on both the child themselves and on the family, and to advocate for their child in the healthcare system and in school. Research suggests that siblings, and particularly those of children with chronic migraine, need help with how to support their brothers and sisters too.

The survey of parents and carers of children with migraine gives us a picture of how long respondents’ children had been impacted for and how frequent attacks were.

Survey of parents and carers

Age when their child had first migraine attack	%
Under 5	26
6-7	16
8-9	17
10-12	21
12-13	16
14-15	4
16-18	1

Sample: 139 parents/carers of children with migraine

¹⁸ Welsh Government (2017). ‘Supporting learners with healthcare needs’. Available at: <https://gov.wales/sites/default/files/publications/2018-12/supporting-learners-with-healthcare-needs.pdf>

¹⁹ Northern Ireland Department for Education, ‘Support for pupils with medication needs’. Available at: <https://www.education-ni.gov.uk/articles/support-pupils-medication-needs>

How often does their child experience a migraine attack?	%
Less than once a month	21
Once a month	17
Twice a month	18
3-5 times a month	20
6-7 times a month	5
8 or more times a month	18

Sample: 139 parents/carers of children with migraine

When asked if they feel that they have enough knowledge about and understanding of migraine to help their child, only 26% felt that they “always” did (26% “often” did, 35% “sometimes”, 11% “rarely” and 1% even said “never”). Asked if their child shows or says that they are upset because of their migraine, 28% said always, 30% said often, 32% said sometimes and 9% said rarely.

- “It will pass but it is very scary when they lose their sight with a migraine” – words of a parent/carer
- “I can’t explain it” – words of a parent/carer
- “He knows what it is because from very young age he [has taken] care of me when I have them” – words of a parent/carer
- “This is a hard question as I don’t really know how to explain. I just tend to say that it’s one of those things you have to learn to live with, just like I have had to and his grandad has had to” – words of a parent/carer

In terms of ways that parents/carers were concerned about the impact that living with migraine had on their children, they answered:

- Education (70%)
- Mental health (67%)
- Overall health (65%)
- Ability to take part in extracurricular activities (57%)
- Ability to socialise with other children (52%)

Asked how often their child had to stay home from school because of their migraine, over half (51%) said at least once a month. 85% of parents/carers had spoken to their child’s school about their migraine, but only 17% were completely satisfied with the support from the school in managing their migraine.

Conclusions

This research underlines that migraine is a serious issue for many children and young people, affecting as many as one in ten children in terms of the quality of healthcare they receive, their experience of school and educational attainment, and their family life. However, there are a variety of steps that can be taken across these three spheres to improve identification of migraine at an early age, standards of care, and reasonable accommodation in education settings. The Migraine Trust is keen to work with health services, the education system and, through them, with children, young people and their parents to strengthen support and develop appropriate materials and policies.



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