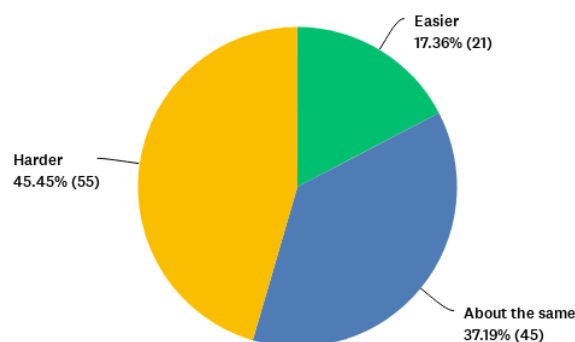


IIH – Life in lockdown

In March 2020 the UK and world experienced an unprecedented event of a global pandemic Covid-19. In the UK lockdown started on March the 23rd and IIH UK was keen to capture the impact on the lives of people with IIH. A great response was received to the IIH UK short survey about lockdown. 121 people responded to the survey which ran from 24/05/2020 to 24/06/2020. 120/121 who responded added additional comments to explain their response.

Q1 Life in lockdown with IIH is....



Most people felt that life was easier or about the same (54%) however 45% felt that life in lockdown with IIH was harder.

For those who felt it was easier

An overriding theme was that working from home was a positive as people were able to pace themselves and rest when needed. Being able to adjust your environment for work such as lighting and noise levels was a benefit. Stress levels were reported by some as less and being able to take better care of self was highlighted. The lack of a commute and rushing around to get to work were also positive. Having less social pressure and interactions was mentioned which can be a source of stress. Family having to stay home as well so that the person with IIH isn't holding back them back was mentioned.

“I have been working from home rather than in an office of 100 people. I have not had the stress of commute and childcare. I have been able to control my environment which has helped me to see a reduction in my headaches”

“I have experienced much less flare ups than I did previously, I've been able to look after myself and notice the signs better of when I need to slow down which has contributed, I believe, to a clearer head”

“The usual pressures of getting out of the house to do the shopping, see people and juggle everything alongside being really poorly have eased. It's easier to pace myself”

“I have experienced much less flare ups than I did previously, I've been able to look after myself and notice the signs better of when I need to slow down which has contributed, I believe, to a clearer head.”

For those who said it was about the same:

The overwhelming theme was that IiH is like lockdown anyway with regard to staying at home and not being able to participate in work or social activities. Some people felt that lockdown was giving others an insight into daily life of someone with IiH. Some discussed a mixed picture of positives and negatives, less stress in some areas such as work but more in others such as lack of access to medical professionals or not being able to be active which was affecting their mental health.

“IiH is limiting - it feels like everyone has joined me in my limited world”

“Well don't go out due to pain etc. so used to being in my own lockdown situation”

“Staying at home is normal for me, due to feeling ill and fatigued a lot. So Life hasn't changed for me as much as it has for most people. It is nice to feel in the same boat as everyone else for a change.”

“Slower pace of life when at home. Little expectation to get out - I can get real rest Unfortunately my job is a lot harder due to COVID”

“Better work life balance at the moment much less pressure and stress surrounding work but on the other hand can't access medical support as normal”

“The headaches aren't any worse. My mental health is as I usually go out walking as often as possible”

For those who felt that life was worse in lockdown with IiH

Challenges of access to medical care was a common theme with cancelled appointments, unable to get hold of medical teams and a lack of information. Dissatisfaction with telephone appointments was highlighted due to the challenges of remembering information. Access to medication and shortages were also a challenge and source of stress. Not wanting to burden medical services was mentioned and trying to cope and self-manage at home. Working from home for some was more stressful because of family being around. For some of those in keyworker roles the increased stress and pressure from work has made their IiH worse and increased symptoms. Less access to friends was noted. A general feeling of stress and pressure was discussed with reported affects on their mental health. The complications of shopping in lockdown were highlighted particularly for those with visual challenges and memory changes with new systems and lack of usual products. A reduction in activity and increase in weight was highlighted and concern about how this impacted on their IiH.

“Lockdown has made it harder to get appointments, medication. It has also worsened my symptoms due to stress and fear of the unknown. However it has allowed me more time to rest and recuperate and more time for my family & partner to understand the Illness which is a positive”

“Less access to friends in person, less access to doctors. Lack of information on how to cope in different situations. Mental health has decreased significantly”

“The scheduling of going out to buy essentials is hard and with headaches and blurred vision it’s even worse. You don’t want to be queuing ages to get in the shop then have the hassle of 1 way systems and forgetting items and panicking about viruses and germs. It’s overwhelming at times”

“Cancelled appointments relating to IiH. Worried about papilledema but not able to get my eyes checked unless an emergency”

“Feeling that my iih is nothing compared to the virus and I shouldn't complain and so trying to manage symptoms at home on my own”

“In some aspects, lockdown has eased some of the issues that IiH was presenting for me. I am able to work from home so I haven't had to deal with going into the office and the challenges that my IiH can present there. However it's been harder to communicate with my healthcare practitioners and harder to get my tablets.”

“Having to work remotely from home means I get no break or respite plus none of the DSE adjustments that were made at work and the stress has been affecting me and my sleep”

“With IiH my only form of getting about was my car. With lockdown I was dependent on others for everything. I haven't been in a supermarket, or out at all since January. My only exercise was walking with the trolley around supermarkets. My muscles weakened, my headaches got worse, and my general health suffered”

Life in lockdown has undoubtedly had an effect on everyone’s lives. Greater levels of stress/ anxiety have been reported in other lockdown surveys (55% for Great British Lockdown Survey). Worsening of headache in lockdown has been reported for those with migraine 55%, alongside a lack of access to medical care and advice (<https://www.migrainetrust.org/the-impact-of-the-crisis-on-migraine/>). One of the most highlighted positives was the ability to work from home and to self-pace apart from those who were in key worker roles or where lap top use affects headaches.

A reduced level of activity and gain in weight over lockdown is concerning as this can impact on IiH symptoms and an increased BMI has been related to a greater risk from Covid-19.

For people with IiH of particular concern is the lack of access to medical care at the right time and reliance on the person to recognize that their IiH needs urgent attention. IiH can result in the loss of sight and the potential for numbers requiring emergency interventions may increase as a result of lockdown. It is vitally important

that people with IAH and worsening symptoms can access the care and information they need at the right time.

As the country comes out of lockdown we have an opportunity to reflect on the experiences reported during lockdown to support people with IAH in the future. IAH UK are sharing the results of the survey with relevant bodies to highlight both the positives but also the greater challenges that people have experienced.

Thank you to all those who took part in the survey and for their insightful views into life in lockdown.