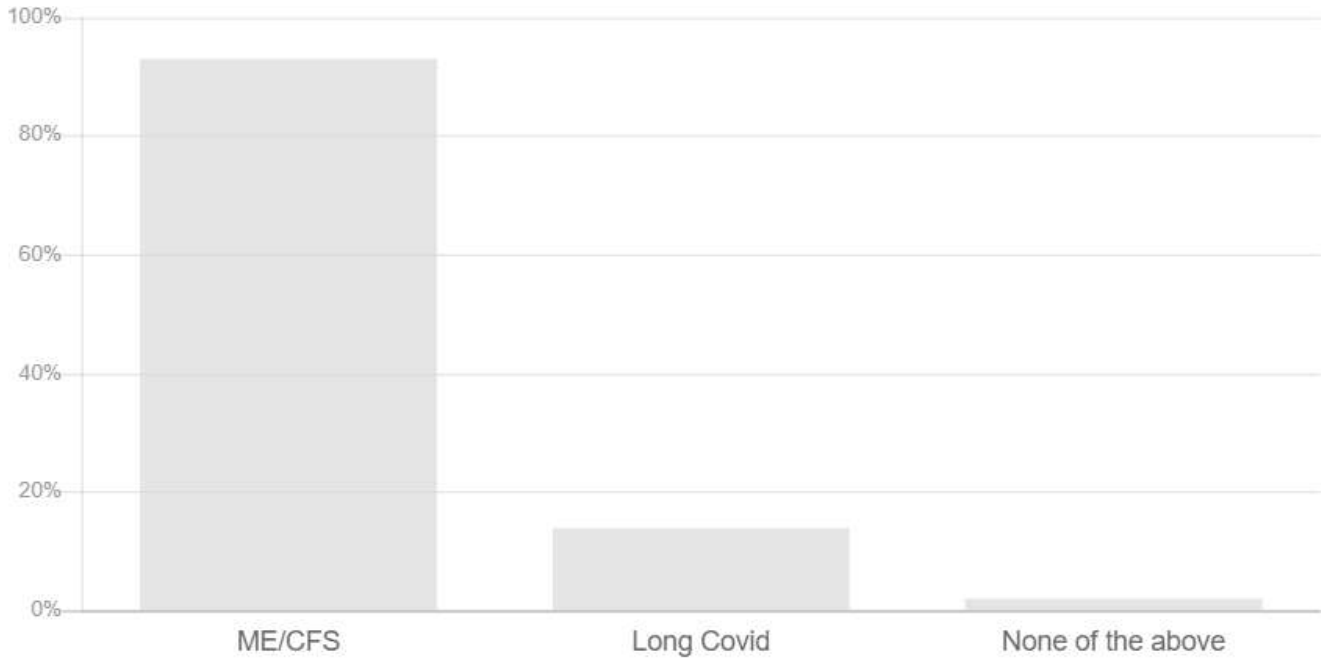


Alcohol Survey

Question 1 CHECKBOXES

Do you have a diagnosis of ME/CFS or Long Covid?



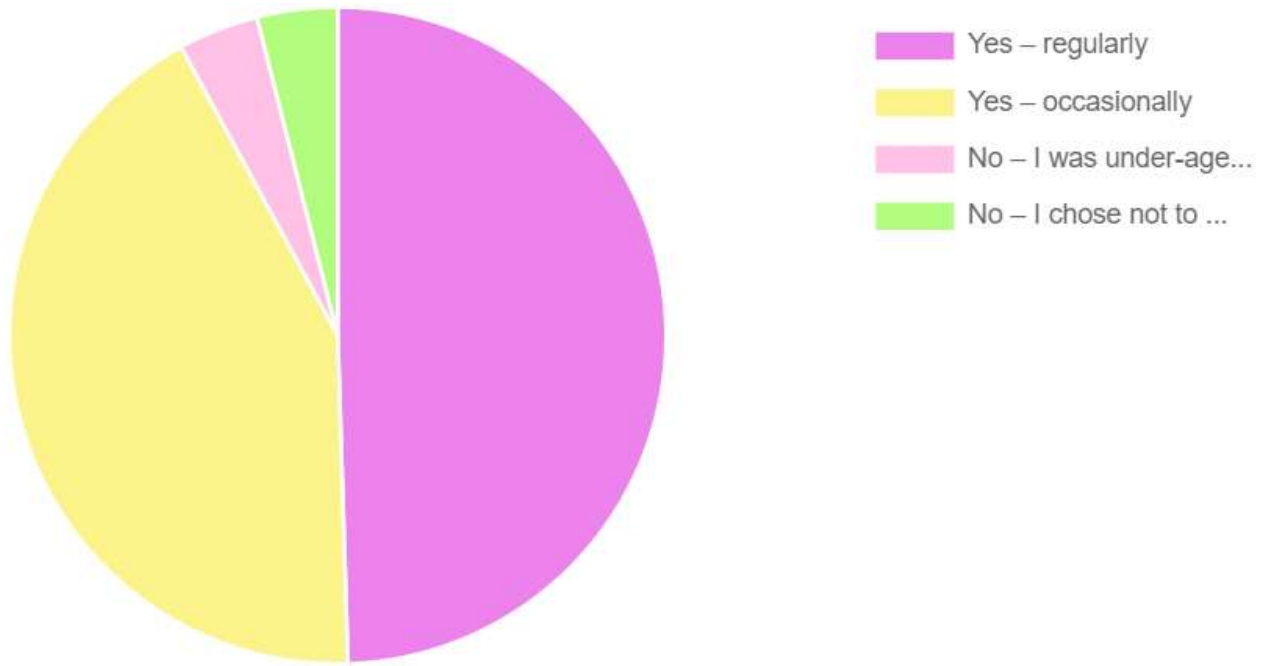
ANSWERS	RESPONSES	
ME/CFS	93%	789
Long Covid	14%	116
None of the above	2%	15

852 Answered

0 Skipped

Question 2 MULTIPLE CHOICE

Did you drink alcohol before developing ME/CFS or Long Covid?



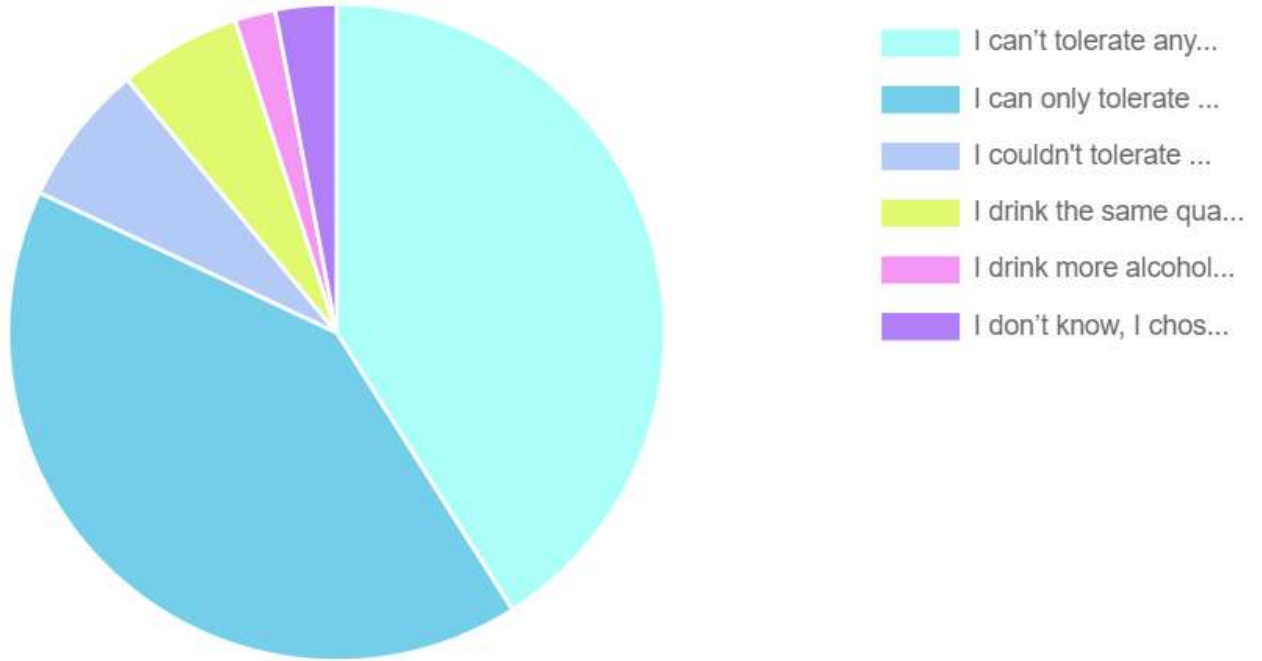
ANSWERS	RESPONSES	
Yes - occasionally	43%	357
Yes - regularly	50%	415
No - I was under-age.	4%	32
No - I chose not to drink alcohol and still don't	4%	33

837 Answered

15 Skipped

Question 3 ☰ MULTIPLE CHOICE

Has your tolerance to alcohol changed since developing ME/CFS or Long Covid?



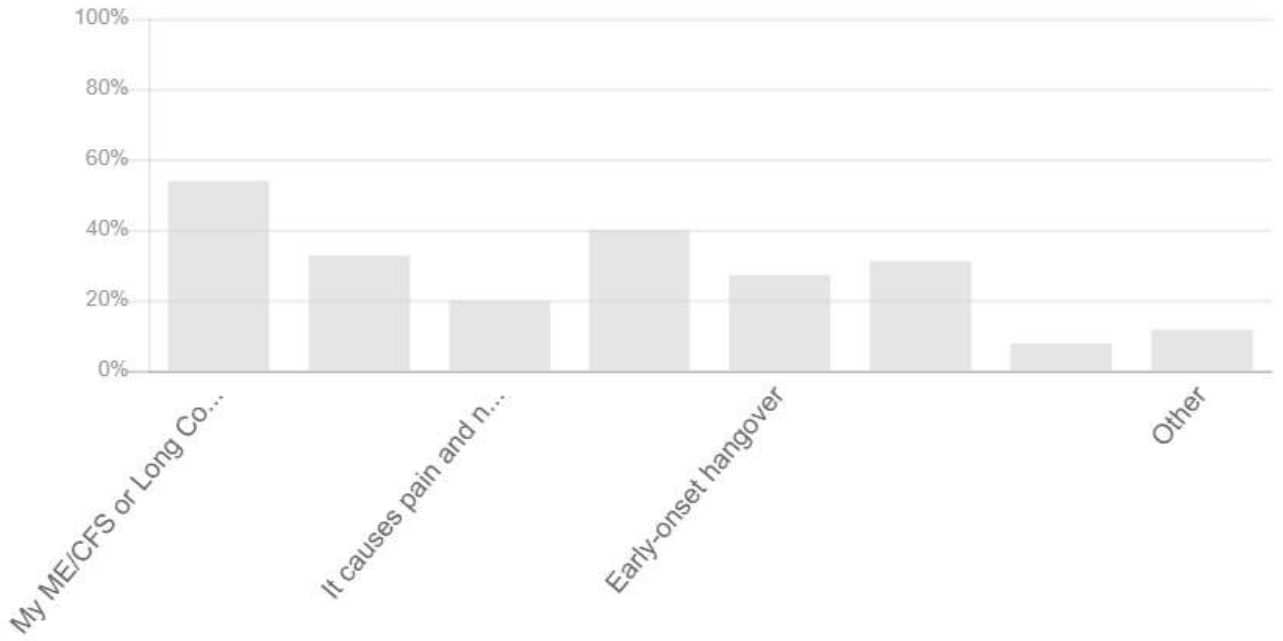
ANSWERS	RESPONSES	
I can only tolerate small occasional amounts	41%	325
I couldn't tolerate any alcohol initially, but now find I can drink again	7%	55
I don't know, I chose not to drink any alcohol	3%	28
I can't tolerate any alcohol now	41%	327
I drink the same quantity of alcohol as I did before	6%	52
I drink more alcohol now than I did before	2%	14

801 Answered

51 Skipped

Question 4 CHECKBOXES

If you have tried drinking alcohol since your diagnosis, which of the following occur?



ANSWERS	RESPONSES	
My ME/CFS or Long Covid symptoms increase in intensity	54%	419
I feel like I have been poisoned	33%	260
It causes pain and no pleasure	20%	153
I feel drunk very quickly	40%	315
Early-onset hangover	27%	207
Exacerbated hangover	31%	243
None of the above	8%	66
Other	12%	96























780 Answered























72 Skipped



















Question 5 SINGLE LINE TEXT






















Other affects from drinking alcohol

ANSWERS	DATE	
My head feels like it's spinning after a very small taste	December 4, 2023 at 10:59 am	

ANSWERS	DATE	
Histamine reactions. Itchy and rash	December 4, 2023 at 11:07 am	
And a very flushed face	December 4, 2023 at 11:09 am	
I don't feel like or able to have a second drink	December 4, 2023 at 11:14 am	
It makes me feel sick, even though I never drink more than one unit.	December 4, 2023 at 11:17 am	
Quite a big energy drop ("drooping")	December 4, 2023 at 11:19 am	
Joint pains	December 4, 2023 at 11:23 am	
Deeply depressive mood the next day, far worse than pre ME	December 4, 2023 at 11:29 am	
Much worsening of fatigue	December 4, 2023 at 11:35 am	
Alcohol always effected sleep - but sleep disturbance more of an issue with long covid	December 4, 2023 at 11:43 am	
Feel more fatigued the next day	December 4, 2023 at 11:44 am	
I get a cough plus more fatigue	December 4, 2023 at 11:48 am	
I get a sudden intense aching heaviness in all my limbs, lasting a few moments.	December 4, 2023 at 11:55 am	
Nausea and upset stomach/diarrhea	December 4, 2023 at 12:03 pm	
No tried since diagnosis but it took 7 years to get a diagnosis after initial onset of ME symptoms and I did drink once or twice in that time and felt like I'd been poisoned	December 4, 2023 at 12:06 pm	
Wheezy	December 4, 2023 at 12:06 pm	
Seems to exacerbate three symptoms (which I think have been improved by a low-hoistamine diet):tinnitus, burning feelings in hands, face and feet,	December 4, 2023 at 12:13 pm	
Increased fatigue	December 4, 2023 at 12:13 pm	
Always get a migraine day after. When drinking now I feel fine 1 minute and then I don't know what happens and I have no idea how I get home or what happened even the memories of when I wasn't yet drunk are usually absent. Before cfs, I always stopped drinking after a few drinks as I hate the feeling of being not in control, now my body doesn't seem to recognise when I have drank enough	December 4, 2023 at 12:27 pm	
Head spins, loss of co ordination of limbs	December 4, 2023 at 12:34 pm	
I drink a small amount e.g. 1 unit just occassionally, much less than i used. Mostly I don't feel the inclination	December 4, 2023 at 12:38 pm	
Shoulder pains and stomach pains	December 4, 2023 at 12:40 pm	
Burns mouth - side effect of Sjögren's	December 4, 2023 at 12:42 pm	

ANSWERS	DATE	
It usually helps me relax, particularly when 'wired', overstimulated or when I've overdone it.	December 4, 2023 at 12:52 pm	
wine tastes terrible	December 4, 2023 at 12:53 pm	
I get migraines	December 4, 2023 at 12:53 pm	
Racing heartbeat.	December 4, 2023 at 12:56 pm	
With a very little I feel better- fuel?	December 4, 2023 at 12:59 pm	
I can't sleep - insomnia	December 4, 2023 at 1:04 pm	
Breathing difficulties just from airborne alcohol	December 4, 2023 at 1:17 pm	
Flushing quickly, unsteadiness and my ME symptoms worsen for several days, and that was just with a small sample at grocery store!	December 4, 2023 at 1:24 pm	
Palpitations and tachycardia	December 4, 2023 at 1:43 pm	
Can onky tolerate a little	December 4, 2023 at 1:47 pm	
Skin flare up	December 4, 2023 at 2:04 pm	
Wanted to sing after few sips of wine	December 4, 2023 at 2:13 pm	
Sudden onset of extremely low mood within 10 minutes. Even tiniest traces of alcohol make me feel bad.	December 4, 2023 at 2:31 pm	
Migraine	December 4, 2023 at 2:34 pm	
Just a small amount of alcohol causes runny nose and nasal congestion, with hangover and fatigue the next day	December 4, 2023 at 2:41 pm	
It makes my brain feel even worse than it already does, dizzier, shaky brain sensation, my nervous system's is affected as I feel jittery and on edge and anxiety is ramped right up. Also get tachycardia and palpitations and flushing in my face... but the brain and nervous system symptoms are the worse. It makes me feel absolutely horrendous.	December 4, 2023 at 2:50 pm	
Suagr rush and want to sleep.	December 4, 2023 at 2:57 pm	
Feel very sick and unwell	December 4, 2023 at 3:24 pm	
I feel dehydrated before I've even finished my drink. I also experience shortness of breath.	December 4, 2023 at 3:26 pm	
Almost passed out after half a glass of red wine, years ago. Now don't drink at all.	December 4, 2023 at 3:56 pm	
Very very red face, very quickly.	December 4, 2023 at 4:38 pm	
as an example,if i have 2 or 3 drinks i start to dehydrate quicky and feel exhausted that lasts into the next day,so i've completley stopped drinking for nearly a	December 4, 2023 at 5:36 pm	

ANSWERS	DATE	
year,and don't know when i'll have another alcoholic drink.		
Pain in bladdet and kidneys. Nausea	December 4, 2023 at 5:44 pm	
Bright red face, start sweating	December 4, 2023 at 5:57 pm	
Anxiety. I have to limit myself to 2 drinks to minimise ill-effects.	December 4, 2023 at 6:00 pm	
Facial skin redness	December 4, 2023 at 6:00 pm	
Hate the smell of wine	December 4, 2023 at 6:24 pm	
Fingers and toes swell, go red and burn	December 4, 2023 at 6:31 pm	
Sleepiness	December 4, 2023 at 9:19 pm	
Palpitations and tachycardia	December 4, 2023 at 9:34 pm	
Extreme oppressive sort of fatigue that's extremely unpleasant, I feel decidedly weird and generically unwell	December 4, 2023 at 10:39 pm	
My knees go funny and it happens immediately. I can tell if there was alcohol in something I've eaten or drunk by the sensation in my knees.	December 4, 2023 at 11:37 pm	
An increase in my resting heart rate to regularly above 100bpm	December 5, 2023 at 5:27 am	
immediate anger and depression	December 5, 2023 at 9:09 am	
Exacerbates tiredness	December 5, 2023 at 11:57 am	
It causes unpleasant and vivid dreams that night and brings on my symptoms the next day just like a PEM hit, particularly cognitive fatigue. So yes I can tolerate some alcohol albeit in smaller amounts and drinking more carefully. Suggest you look at coffee consumption as well-this very quickly makes me crash and brings on my ME symptoms, whereas other people I know with ME can drink copious amounts. I therefore don't think it is useful using zero tolerance to alcohol as a key diagnostic feature with ME-it is very much an individual thing-whether it be tolerance and sensitivity to alcohol, coffee or other foodstuffs you ingest. I think this no tolerance to alcohol is therefore very misleading in ME and is often inappropriately used by the ignorant, especially some of the medics out there. To be told that I can't have ME as I occasionally drink alcohol is somewhat wearing after a while.	December 5, 2023 at 1:53 pm	
It's difficult to describe, it just made me feel worse, ill. Then my ME got worse and I haven't drunk alcohol since.	December 5, 2023 at 3:11 pm	
More likely to have memory issues the next day	December 5, 2023 at 6:12 pm	
Wine just tastes of alcohol, spirits unbearable. Beer ok but I don't feel well enough to enjoy it.	December 6, 2023 at 6:06 pm	
It improves my cognitive function if I have a single alcoholic drink everyday.. Without it I deteriorate into a deep brain fog. I have speculated that it is to do with	December 7, 2023 at 10:31 am	

ANSWERS	DATE	
the blood thinning effect of alcohol.		
my limit now is 2 whiskies or two glasses of wine. Thereafter I feel the effect of the alcohol which puts me off further intake.	December 7, 2023 at 8:41 pm	
High heart rate for hours following drinking. This starts 3hrs after consumption	December 8, 2023 at 2:25 pm	
If combined with social activities my me/cfs symptoms increase & I need a l	December 8, 2023 at 2:26 pm	
I feel dizzy with only a very small amount & don't get the merry feeling I used to get	December 8, 2023 at 2:30 pm	
Disassociation, anxiety	December 8, 2023 at 2:43 pm	
I simply have no enjoyment - it's not the flavour, it's just my body says "no thanks, I don't fancy that"	December 8, 2023 at 3:13 pm	
Vertigo and reflux from just 1-2 drinks	December 8, 2023 at 4:00 pm	
I feel better. It completely eliminates my ME/CFS symptoms, including PEM.	December 8, 2023 at 4:58 pm	
Tingling feet / restless legs	December 8, 2023 at 6:13 pm	
Makes me feel better for a short time and gives me energy	December 8, 2023 at 6:31 pm	
Below effects occasional not every time	December 8, 2023 at 6:38 pm	
Flushing immediately, then chest and other muscle pain, palpitations, feeling generally very unwell	December 8, 2023 at 10:20 pm	
Dizziness and light headedness	December 8, 2023 at 11:38 pm	
tachycardia	December 8, 2023 at 11:47 pm	
I feel better after alcohol, most of the time: it's like my blood circulation finally works properly (mostly red wine). no	December 9, 2023 at 7:04 pm	
And additional headaches, nausea, and less able to communicate and feeling "out of it". I'm talking about literally a few sips!! I did have a small amount once which didn't have this impact, but the other 2 or 3 times I tried in the past 3.5 years meant that the impact was not worth it, because while it was nice to taste I then just felt worse.	December 9, 2023 at 7:31 pm	
Tachycardia	December 9, 2023 at 11:19 pm	
Racing heart rate	December 10, 2023 at 10:21 am	
I can tolerate wine or beer, but not spirits.	December 10, 2023 at 4:47 pm	
Feeling agitated and unable to sleep. I had one glass of red wine with evening meal. Never again!	December 11, 2023 at 8:58 pm	
It tastes wrong now.	December 12, 2023 at 10:35 pm	

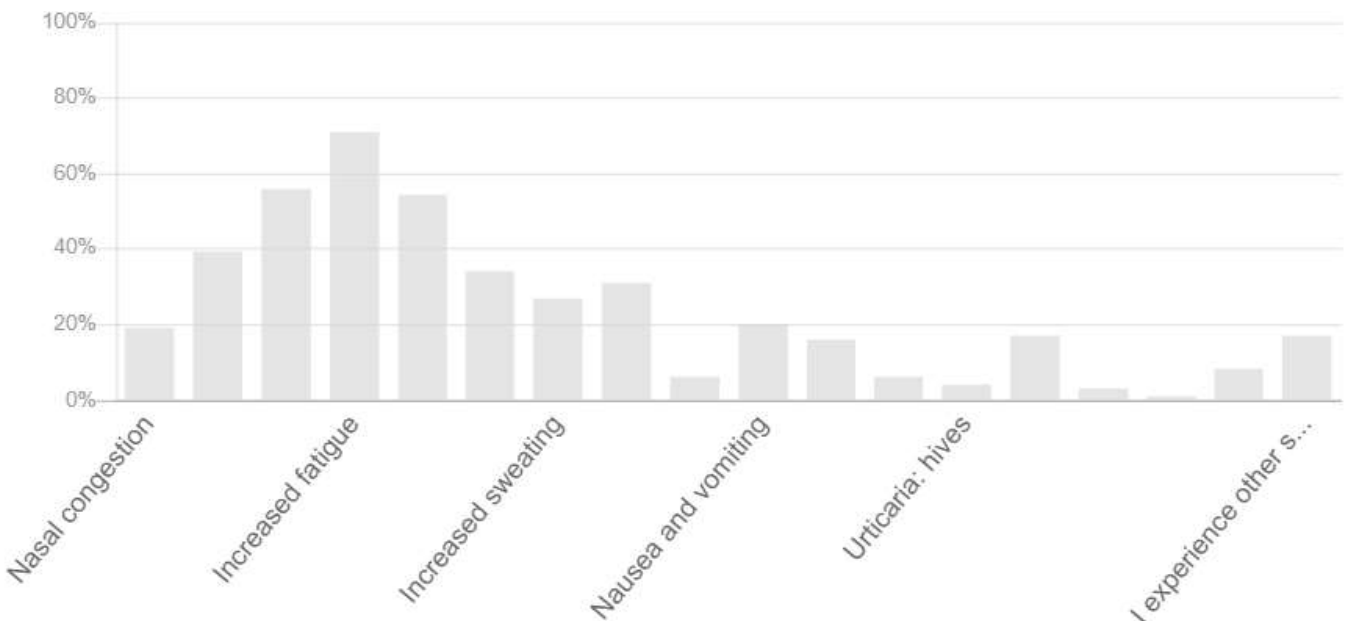
ANSWERS	DATE
Vomiting, maybe 10 hours later, but this could've been my now-realised reaction to 'overdoing it'	December 13, 2023 at 12:22 pm
Causes heart palpitations.	December 13, 2023 at 11:06 pm
The word is EFFECTS.	December 16, 2023 at 2:41 am
Almost fall asleep, literally nearly fell into my meal in a restaurant after a previously manageable amount of alcohol	December 16, 2023 at 7:02 pm
Extremely hot and painful rash on face and left arm In a circular patch	December 17, 2023 at 12:33 am
I can tolerate alcohol in smaller quantities than before illness.	December 17, 2023 at 3:08 am
Hot flushes	December 18, 2023 at 2:39 pm
Nausea, headache	December 29, 2023 at 1:10 am
I feel like I've been set on fire & get a red rash from the top of my head down to my chest & feel sick.	January 10, 2024 at 12:59 pm

93 Answered

759 Skipped

Question 6 CHECKBOXES

Do you experience any of these symptoms after drinking alcohol?



ANSWERS	RESPONSES	
Nasal congestion	19%	144
Skin flushing (redness)	39%	298
Headaches	56%	432
Increased fatigue	71%	544
Increased sleep disturbance	54%	414
Increased temperature	34%	260
Increased sweating	27%	206
Increased heart rate *	31%	237
Low blood pressure *	6%	45
Nausea and vomiting	20%	156
Stomach pains	16%	120
Skin rash	6%	44
Urticaria: hives	4%	30
Diarrhoea	17%	133
Difficulty breathing *	3%	22
Swollen tongue *	1%	9
None of the above	8%	61
I experience other symptoms	17%	127

766 Answered

86 Skipped