

Social Media Research Study: What Risk Camp Are You In?

Determining the level of risk coeliacs are comfortable with when eating out

Raw Data (comment responses to social media post) Ref BLOG – “RESEARCH: Which Risk Camp Are You In?”

Conducted May21 2019 J.Thompson (Gluten Free Joy)

(Note: some comments incomplete)

Facebook: @glutenfreejoy17

Post

C.. Happy to say yet to be glutened at the places I choose to eat at ... have a local place that is amazing for Coeliacs with CC ☹️👩🏻 so tend to stick with it anyway

I'm a C most of the time, my choices are defined by the fact that I have managed my condition in this way from day dot with little to no impact with regard to major glutening episodes alongside perfect yearly blood test results and multiple follow up

C, my friends let me pick wherever we go out so I have a few safe places. I won't however eat things my friends have made if I haven't seen it made

C for me and my 2 yearly follow up biopsies confirm that it is possible for me. In 9 years I've only had 4 episodes of being glutened.

C for me

C, choosing c I have been out where I haven't been able to eat as the claims of gf hasn't been the case due to cross contamination ☹️.

C for sure- if I don't feel the staff/ friends know what they are talking about with regard to their food prep and ingredients then I politely decline.

E: I run a combo of A-B-C and constantly eat where I know it's safe(Nando's, sushi or glutenfree4u) or simply a packet of Smith's original chips when out and about to die of starvation. 2years since being diagnosed I'm still learning loads but the biggest

I used to be a mix of A & B but now I'm in the C category ☹️

I float between A at times.....and D. I don't get huge symptoms. Achy spine and joints afterwards which subsides after a few days once I'm eating 'clean' again. My symptoms increase the longer I am exposed to it. I do like to try and ensure long gaps

C. I also have a bunch of food allergies, so there is always a bit of risk somewhere. Otherwise I would never be able to go anywhere. And I like to travel too much. I generally choose to cook for myself over eating out

And it's a C for me!

I'm a C

Use to be A - B but life got lonely, hard and stressful so now it's a C...

I've been coeliac for 23 years and at the beginning I was A not much knowledge around then but now more towards C as I find more people are more aware of the disease

C for me and have walked out of lots of places that don't get it, but it's getting better. I had a great experience Barwon Heads Hotel where I ordered a Gf item off the menu, the chef came and told me he wasn't happy for me to have it as he thought it

C is such a good description

I was C but after some bad experiences of being glutened and health issues I've become even stricter so now B

There has to be something between C and D. I'm definitely not D. I try not to take too many risks and I never knowingly eat gluten. But I don't fit into C either, because I don't "check the coeliac safe food practices of a venue before committing to dine home kitchen is covered in gluten toast crumbs (my kids!), which I do my best to clean up, so who am I to quibble about a shared kitchen.

Rachel Henderson yep, I get that ☹️...my home kitchen also a shared one...I have my own 'space' but my 22 year old has been known to use it for his random 'bread on bench' food prep ☹️...I also clean my own boards etc...don't trust the males to use tl

Rachel Henderson same

Same!

Ah this is always an issue in my home too. They have a gluten service area and are well trained on using butter ect. Mostly they are good. I find it is my fiance more than the kids that does my head in here.

C- the last "glutened" meal I had was an accident and I understand but the outcome was terrible so I have been much more careful recently but mainly I have found that if I tell the cooks or wait staff that it's an allergy they are more careful. Most of tl

I think I'm kinda D. I'm a bit of a cowboy as I don't get symptoms. The times I eat out I try for GF but not many options around here so occasionally just indulge and end up with headaches for a couple days.

B and C

B and C..depending upon how I got my last 'Glutening'..

C for me... worse case.. wine is a GF option ☹️ For my 8yo unless staff show 100% confidence she will refuse and stick with her own lunch (which we bring everywhere)..

C. But, most often I choose not to eat there so would border with maybe B.

C. And sometimes choose to not eat because i cant find safe food.

More of a C, with a bit of B. thrown in. I always check out restaurants and will not eat there if even a slight chance. My husband or I usually “supervise” in the kitchen when we eat at friends places. I have walked out of restaurants that have not lived C but make sure I am confident with the venue and tend to have a small group of places I will dine at. I am more likely B if away from my home area.

Somewhere between C and D. I’m definitely not a “cowboy” and make sure that what I eat is gluten free by ingredient but I also understand that to have a normal social life I need to be prepared to accept some risk. I don’t research any further than r Amanda Rogers I’m exactly the same. Not C. Not D. In between.

B for me

C and occasionally D.

I think I’m kinda D. I’m a bit of a cowboy as I don’t get symptoms. The times I eat out I try for GF but not many options around here so occasionally just indulge and end up with headaches for a couple days.

Somewhere between b & c. Symptoms are not worth it ☹

C - I wish there were more 100% GF venues. I think one just opened in Maitland Gaol so that’s exciting!

Between C & D I’m 63 have no symptoms was diagnosed 5 years ago so careful but not obsessively

C mostly but at times clearly B

B and C for me

Oh very hard , I’m usually A but have recently dined out 3x but throughly checked out venue restaurant etc , I won’t eat at places that I’m not confident about at all

C. But more 'eat out when necessary' than 'choose to socialise'. 'eat nothing' is often my preferred option

A mostly, but sometimes C. Have been blessed with some amazing friends who really get it and cater!!

C - me and both kids (8 and 11) - all for mental heath reasons. My friends let us pick the venue most of the time.. I do get severe symptoms of glutening within 30 minutes, but feel the “start” of it coming on within 20. So I know I have 10 minutes at le boundaries of CD, without missing out all the time. I already see the anxiety CD causes them. This is why C is the only option for our family.

Nicola Love yep. It’s really tough for kids because the social isolation aspect is a particularly big deal. I do have another Eat Street Kids GF Party at Eat Street coming up end of June, so keep that in mind as they love the inclusivity aspect of it. ☹

Great descriptions A and occasional BMy daughter and I are celiacs. There are literally only two restaurants I eat at in Brisbane. Would love to know others.

I tend to eat at home more than out!

I’m a bit of b & c..I can be funny about friends prepping food for me but I do enjoy being social & getting out. I do research menus & when booking like to put a comment about needing to be gf for me. Will usually byo at friends. Especially if there’s a always tired & I feel itchy sometimes so take antihistamines which make me even more tired! I do sometimes go without a meal as I know I’m not being understood & that things may be contaminated. So I’ll just order a wine ☹ ‘ other times I eat befo

I'm a B, occasionally C. There are only 2 restaurants that I feel comfortable eating at on the Sunny Coast.

Nicole Louise oh which are those?

I also occasionally eat from Bombay bliss in Coolum- but still ask every time and show my Coeliac card.

Gluten Free Joy Goodness Gracious Organic and Gluten Free Cafe at Yandina is my favorite. :) Jill and the team there are wonderful.

Nicole Louise yep I haven’t been but so keen to go there!

Gluten Free Joy you definitely should!

And it’s a C for me!

C; but only for special occasions and have so for never been glutened. I have only ever trusted my closest family or best friend to cater for me at their houses and will take my own food to Bbqs.

I am a C. I was an A to B for a long time when first diagnosed. Particularly after my first severe reaction was from eating out at a recommended place. However I am very social as a person and I love exploring food. As this have become more aware (al to only frequent tried and trusted venues.

I am 50% A and 50% B and it’s just not worth giving something a try if I am not 99% sure because of how sick I get when I do get ‘glutened’ and also my body struggles and is slow with healing it self after I have been ‘glutened’. So unfortunately this dc

Seza Bel yep really tough... it’s just not worth the risk when you get so sick.

Though I do have to say since I have reading your posts and blogs I have been very tempted to go out and try a lot of new and different places ☹

C I take my health seriously but think cultural experiences and social interaction are important. I am more wary at friends houses than eating out. My daughter and I were diagnosed 4 years ago and our bloods have been perfect for the last 3.5 years

Instagram: @glutenfreejoy

Comment

I'm C borderline B. I'll eat out with lots of research and have been accidentally glutened once or twice. However I'm not confident enough to eat at friends places so cater for myself to elevate burden for them and anxiety me.

D 🙄

C

B/C most of the time I will avoid eating out

C/D

C

B/C

C

At the moment, A ... 🙄

🙄% C

@nine_foxes is that because your symptoms are really bad?

C. But a very very diligent one. I go out very rarely and will only eat at 100% GF cafes/restaurants and if they are not 100% GF they must be already approved by the coeliac community as safe and I feel comfortable with their practices. I take my own f

@itsjustmerenee yeah I bet. That's not fun. Non 100%GF places definitely tricky for you as even the most diligent research is not a guarantee...always a risk that one person in the food prep chain makes a mistake. But yes, when you find one that doe:

@glutenfreejoy you can't live in a bubble, quality of life is important. I have my small handful of safe places, I am a return customer and am not afraid to question their practices every time. I am very lucky my family and friends understand how dange

@itsjustmerenee yeah sane...I have very understanding friends and family 🙄

C

C. I've very rarely been glutened while eating out (and I react quickly too.) I think a large part of the gluten free lifestyle has to be about mind set and how you approach and cope with it.

@champagneandgumboots yep, the mental health side of it is real. Isolation and food anxiety can be a big deal, so it's important to manage it the way that feels right for you.

C

C

C... And often only order what I determine as a 'safe' salad. And with a lot of anxiety, both at restaurants and friends/relatives.

@iamjudijami yep. The hidden stress. It's crazy. Even just having to ask all the questions is stressful but you know you have to!

C. 100% glutenfree venues are very scarce in Germany. I communicate a lot about the coeliac requirements - in restaurants and towards friends and family. Sometimes it is frustrating - when you explained everything and still get glutened. But it happ

@glutango_blog yeah exactly. Really important to give feedback to help them improve any practices that might be letting them down. Takes bravery though!

C to D. I feel like either I don't react that bad anymore or eating things cooked in same fryer rarely actually contaminates. Otherwise I'd never be able to eat chips or have toast out, and doing this I have never gotten a reaction. Other than eating chip pleasure

@melting_peaches yep I get it. Mental health with managing it really important. So interesting though that almost 20 years on still very asymptomatic! Curious to know if in your case no symptoms indicates no damage? Have you had any follow up er

@glutenfreejoy no I haven't had an endoscopy since I was 8 years old!!! All my bloods seem to be okay, but I'm going to the doctors soon as I have been having a lot of pain recently for the first time since I was a child in my lower left abdomen for an If you have Coeliac disease eating gluten will certainly cause internal damage despite not having any outward symptoms. Many people are non symptomatic and only discover they have Coeliac when another family member tests positive - however v

would never have chips that have been fried in the same fryer or bread toasted in a shared toaster. Now if I accidentally eat gluten I am extremely sick with 1-2 hours. I'm sure this is because I have kept it out of my body for so long now and it's an au

What an interesting question! I'm a C, but I feel like I'm pretty cautious all the same. I also use a Nima which makes me more confident and I only eat out when it's "worth it" (so maybe 2-3 times month?) I feel like I take my health seriously but never

C

C

C. I've reacted worse as I've got older. If places don't have gf options on the menu I usually go somewhere else because I feel they probably don't really want me eating there haha.

@whitneyderrick yeah same. My poor family are so use to going from one place to the next until we finally find somewhere that has GF and I feel I can trust them re CC ...if they won't cater for me then they don't deserve to have the rest of the group

@glutenfreejoy exactly 🙄🙄

Used to be a D but getting worse reactions as I get older so now a C

B

C

Cowboy 🤠 lot's of risks

Cowboy 🤠 lot's of risks

Somewhere between B & C. But I used to be A!

@stubbornmomdotcom thanks so much for the feedback. Can I ask what caused the change?

@glutenfreejoy trust over time. Trial and error. Not wanting to live in fear. Figuring out my diet.

@stubbornmomdotcom yep, that sounds familiar! It's learning how to live with it I guess...and not just hide away which can be just as bad for your overall mental health. Thanks for connecting 🤝