Questions and Answers



on the Social Aspects of Multiple Chemical

Sensitivity (MCS)



Empowering Community and Removal of Barriers (ECRoB) Project

Has MCS been called by other names before?

Across various contexts and throughout different periods, alternative terms have been used to refer to Multiple Chemical Sensitivity (MCS), illustrating the evolving comprehension of this condition. Additionally, MCS has been identified through a range of other names, which include:

- allergy syndrome (Piroli et al., 2013)
- chemical allergy / hypersensitivity
- chemical injury / intolerance
- environmental illness / environmental sensitivities (Nethercott JR; Davidoff LL, Curbow)
- Gulf War Syndrome
- hypersensitivities (Nethercott JR; Davidoff LL, Curbow)

- intolerances (Nethercott JR; Davidoff LL, Curbow)
- Mast Cell Activation Syndrome (MCAS)
- Multiple Chemical Sensitivity (MCS)
- sick building syndrome
- total allergy syndrome
- toxic-induced loss of tolerance (TILT) (<u>Tilt Research</u>)

How does the naming of MCS influence our perception of disability and health?

The way we name MCS can shape how society views this medical condition. The terminology used not only reflects but also influences public awareness and comprehension of the medical condition, consequently shaping how individuals with MCS are perceived and treated within society.

With the name Multiple Chemical Sensitivity (MCS) - the term 'sensitivity' may not convey the seriousness of the condition and jeopardy that an individual with MCS can be placed in from exposure to chemicals. This may inadvertently reinforce societal attitudes that unjustly place blame and responsibility on the "sensitive" individual rather than acknowledging the larger systemic forces that impact everyone and contribute to the disability, such as ubiquitous chemical use in society, deregulation of the chemical industry, and improper labelling on consumer products.

"TILT," or Toxicant-Induced Loss of Tolerance, introduces a medical perspective, emphasizing the loss of tolerance to certain substances due to exposure.

"Chemical injury" explicitly frames MCS as an injury resulting from chemical exposure. This wording may be impactful in highlighting the harmful consequences of exposure, potentially garnering more attention to the severity of the condition.

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In this document and the project, we will refer to this disability as MCS, while calling attention to the need for an appropriate scientific name that conveys the serious health effects experienced from exposure to chemicals.

What are some barriers to inclusion experienced by the MCS community in social settings?

Individuals with MCS often face challenges in social environments due to exposures to chemicals contained in products or from other sources. These barriers may include:

- lack of awareness and understanding of MCS
- lack of education for first responders, social workers, and law enforcement.
- public attitudinal barriers
- inadequate chemical regulation in Canada
- industry greenwashing and marketing harmful products
- use of masking agents in consumer products
- inaccessible public spaces
- inaccessible transportation
- widespread fragrance and chemical use
- lack of workplace accommodations and workplace discrimination

- limited medical understanding of MCS
- limited legal understanding of MCS
- social isolation
- financial barriers
- inadequate support services and programs
- housing challenges
- lack of legal protections
- insufficient advocacy to government and policy gaps
- stigma, prejudice, and discrimination
- air quality (indoor and outdoor)
- inadequate domestic manufacturing of affordable, fragrance-free, lowest-emission, least toxic eco-friendly sustainable circular economy products

What types of accommodations are important for people with MCS?

Accommodations are important for people with disabilities, including MCS. Here are some basic accommodations for MCS to reduce barriers to inclusion and accessibility:

- 1. **Least Toxic Product Choice:** Use of fragrance/scent-free, lowest-emission, and least-toxic products, decided upon in collaboration with a person with disability.
- 2. **Scent/Fragrance-Free Policy:** Implement, monitor, and enforce fragrance/scent-free policies. Involve individuals with lived experience of the disability in decision-making processes, including policies and emergency planning.
- 3. Flexible Work Options: Allow remote work and flexible hours to accommodate varying exposure risks.



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- 4. **Provide a separate office in the Workplace:** Allow the person with MCS to have their own office and workspace that is not shared. Allow the ability of open windows if possible, and provide an appropriate air purifier.
- 5. **Breaks and Supportive Environments:** Designate trigger-free break areas and provide additional breaks if required.

How can the MCS community contribute to environmental health reform in Canada?

Individuals with MCS can play a vital role in advocating for environmental health reform. By sharing their experiences and knowledge, they can raise awareness about the impact of environmental exposures and factors on health and advocate for policy changes.

How does housing affect individuals with MCS, and what are their housing needs?

Housing significantly impacts the well-being of individuals with MCS. Suitable housing for MCS should be in an area away from polluting activities including industry or traffic emissions, agricultural and golf course pesticide and chemical use, and smoke from various sources. Water damaged buildings or homes should be avoided and materials for construction and renovations must be the lowest-emission and least-toxic. This type of housing can be incredibly difficult to find - especially in a rental setting, and even more so on the lower end of the income scale as affordable, healthy housing is impossible to find. Homelessness for people with MCS does not always reflect poverty, but can depend on the inability to find healthy spaces to live, as people are forced to couch surf, move often, live with their windows open, or live in their cars or tents even in winter. People with MCS are at risk of homelessness if a toxic product is used in their healthy space, and the chemicals cannot be removed. Housing for people with MCS is one of the most important factors of managing MCS and maintaining health.

What challenges do individuals with MCS face in the workplace, and how can these be addressed?

Many individuals with MCS encounter difficulties in the workplace, including exposure to chemicals, discrimination, attitudinal barriers, and a lack of accommodations. Addressing these issues involves creating scent/fragrance-free, least toxic workspaces through product choice and ensuring equal opportunities for all employees.

How can we combat greenwashing and marketing manipulation in consumer products for individuals with MCS?

To combat greenwashing and manipulation, consumers, including those with MCS, can stay informed about product ingredients, always read labels and ingredients every time a product is purchased, always choose fragrance-free products, and avoid products with the term 'parfum' on the label, support transparent labeling and products with certified logos, and participate in advocacy for stricter regulations on advertising and marketing practices.

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What role does climate change and pollution play in the intersection of environmental racism, classism, and ableism?

Climate change and pollution disproportionately affect marginalized communities, which often face higher levels of pollution due to systemic inequalities. This can intersect with environmental racism*, classism*, sexism*, ableism*, and other forms of systemic oppression, impacting the health of individuals with MCS.

How can emergency preparations be adapted for individuals with MCS?

For situations related also to climate change, it is important for people with MCS to proactively prepare for emergencies and disasters. This can involve customizing emergency first aid kits and preparedness plans to meet their specific needs.

The personalized emergency kit should include safe, non-toxic and tolerable items, medications, hygiene essentials, comfortable clothing, and important documents. The emergency plan should cover escape routes, communication strategies, safe meeting spots, emergency contacts, and evacuation plans.

Additionally, it's important to educate others about MCS, regularly practice the emergency plan, stay informed about community alerts, and know local resources such as emergency shelters. Being prepared empowers individuals with MCS to respond effectively and stay safe during unexpected events.

What calls to action can promote the inclusion of individuals with MCS and improved consumer protection regulation?

Calls to action may include advocating for universal design in public spaces, pushing for stronger consumer protection regulation, raising awareness about MCS, and fostering an inclusive society for all individuals, regardless of their disabilities or health conditions.

MCS is a medical condition and recognized disability with varying levels of recognition and understanding. It can significantly impact an individuals' life. Consult with knowledgeable healthcare professionals and patient advocacy groups for guidance and support. Stay informed about the latest research and treatment options, and explore strategies to mitigate the impact of this disability.

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*Systemic Forms of Oppression Definitions:

<u>Environmental Racism</u>: the disproportionate exposure of racialized communities, often Indigenous and minority groups, to environmental hazards, pollution, and toxins. These communities may experience a higher prevalence of environmental risks due to discriminatory practices in the placement of polluting industries, waste sites, or hazardous facilities.

<u>Classism:</u> involves discrimination or prejudice based on socioeconomic class. This can manifest as unequal access to resources, opportunities, and services based on one's economic status. It may result in systemic barriers that hinder the social and economic mobility of individuals from lower socioeconomic classes.

<u>Sexism</u>: the discrimination or prejudice based on a person's sex or gender. Sexism can be observed in various forms, including gender wage gaps, unequal representation in leadership roles, and gender-based violence.

<u>Ableism:</u> discrimination or prejudice against individuals with disabilities. This can include barriers to accessibility, unequal opportunities in education and employment, and social attitudes that perpetuate stereotypes and stigmas surrounding disability. Systemic ableism can limit the full inclusion and participation of people with disabilities in various aspects of society.

<u>Ageism:</u> Age-based discrimination can be observed in areas such as employment, healthcare, and social services, where individuals may face stereotypes or unequal treatment based on their age.

<u>Homophobia and Transphobia</u>: discrimination based on sexual orientation and gender identity is a form of systemic injustice. It manifests in unequal treatment, exclusion, and violence against 2SLGBTQ+ individuals.

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