

Interview with Steve Chalmers

SESSION I (2/21/2020)

Timed Log

Minutes

[00:00:00]	Introduction. Growing up in suburban Los Angeles, CA. Father worked in chemical industry. Childhood exposure to pesticides, fertilizers, and elemental mercury. Theorizes that chemical exposure from conception onward contributes to development of illness.
[00:09:00]	Purchases home in Sacramento with improper drainage and other structural defects. Family members, including young children, begin exhibiting symptoms. Hiring industrial hygienists to conduct extensive testing, including mold testing, on house.
[00:21:57]	Wife experiences symptoms first. Deferring to industrial hygienists' reassurance that house is safe despite wife's intuition otherwise. Spending large amounts of money to continue testing house. Evacuating house after multiple incidents of exposure triggering extreme symptoms in family.
[00:32:00]	Seeking consultations with healthcare practitioners, who deny illness. Context of medical professionals being threatened with losing license if acknowledge MCS.
[00:34:17]	Seeking accommodations for children in school. Limiting extent of demands made in attempt to mainstream children in public school and prepare them to navigate exposures throughout their lives.
[00:39:35]	Seeking accommodations for son in college. Consulting with environmental doctor who validates illness and writes letters for children's schools.
[00:43:14]	Period in California during 1990s and 2000s of doctors being wary of diagnosing MCS due to risk of losing medical license as result of lobbying by chemical industry and disinformation regarding MCS. Founding of and controversy around field of clinical ecology in 1950s. Politics around elevation of allergy alongside delegitimization of MCS. Comparisons with lobbying efforts to deny climate change.
[00:48:52]	Lobbying in Washington, DC to silence references to MCS. Process of coming to understand political maneuvering around MCS.

- [00:52:00] Activism behind-the-scenes via conversations with political lobbyists. Engaging in advocacy for accommodations for children at school and for self at work. Being granted accommodations due to senior-level position in company. Facing eventual repercussions for frequency of telecommuting. Seeking early retirement due to anticipating difficulty finding new job due to MCS.
- [01:01:50] Discussing MCS with boss and coworkers. Approach of engaging in conversation with boss about illness and limitations rather than making demands. Significant decline in capacity to work after critical exposure and chemical injury at sick house.
- [01:09:35] Spending majority of time managing MCS household. Difficulty finding products not manufactured or stored in fragranced facility. Trying to mitigate inflow of neighbors' laundry scents into home.
- [01:15:16] Challenges traveling with MCS. Process of quarantining clothes worn while traveling. Playing massively multiplayer online (MMO) role-playing games as a family in lieu of traveling.
- [01:20:22] Engaging in armchair activism by providing assistance and support via online communities to others struggling with MCS. Repeating three main messages about MCS contradicting theories underlying modern medicine and medical research; wide variance in experiences of MCS; and need for expansive and inclusive definition of MCS to promote solidarity within MCS community.
- [01:27:27] Recounting memory of "Rosetta Stone" moment of experiencing different reactions of four family members to same exposure. Discovering analogy between importance of precise environment for computer CPU chips to function and physical environment impacting psychological functioning.
- [01:32:22] Theory that MCS cannot possibly happen because medicine as currently practiced cannot conceive of it. Heretical hypothesis regarding MCS as based in an environmental attack that removes body's defenses and spreads to binding proteins supporting nervous system operation.
- [01:44:40] Impact of MCS on everyday life. Family effectively homebound due to MCS. Engaging in time-consuming processes for running errands and managing potential reactivity to items.

- [01:46:27] Significant financial impact of MCS on family. Consequences of going out into the world for someone with MCS, which differs according to severity of illness.
- [01:50:04] Relying on family support rather than mental health professionals to cope with MCS.
- [01:51:08] Pattern of dismissal by medical doctors. Learning not to discuss MCS with mainstream medical doctors. Viewing patient as general contractor and mainstream doctor as subcontractor in managing health of patient with MCS.
- [01:53:12] Wife's experiencing of MCS symptoms earlier due to longer amount of time spent in the sick house.
- [01:53:41] Participating in online groups for people with MCS. Experiencing different groups serving different functions in supporting members. Witnessing tendency for members of MCS community to engage in infighting.
- [01:55:42] Desire to see change in basic theory underlying medicine to enable conceptualization of MCS.
- [01:57:44] Father's support for MCS and his own experiences of environmental sensitivities.