

Submission Type: Rule Change

Reference: Accelerating smart meter deployment

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Comments: As a long-term sufferer of Electromagnetic Hypersensitivity (EHS), I am extremely concerned that your document does not recognise the implications, nor propose any 'opt-out' of SMART meters for Australians like myself; people who may have no option other than to go entirely off-grid if this is forced upon us. This amounts to medical discrimination. I have attached a reference document for your information.

Furthermore, I strongly object to the level of private/public partnership control which these meters facilitate; so much so that I intend to become solely self-sufficient if they are enforced.

A snapshot of living with Environmental Sensitivities in Australia in 2019.

By Dr Sharyn Martin

Table of Contents

Section 1.0 Introduction.....	2
1.1 Environmental Sensitivities.....	2
1.2 Origins of Environmental Sensitivities	3
Section 2.0 ANRES Data to October 2019.....	5
2.1 Environmental Sensitivity Conditions Selected	5
2.2 Other Conditions Reported.....	5
2.3 Number of Conditions.....	6
2.4 Common Environmental Sensitivity Co-conditions	7
2.5 Characteristics of people with Environmental Sensitivities.....	10
2.51 Conditions by Gender	10
2.52 Number of Environmental Conditions by gender	11
2.53 Onset and duration of conditions	11
2.54 Diagnosis:	13
Section 3.0 Burdens/Hardships experienced by those with Chronic Environmental Sensitivities	15
3.1 Hardship Categories selected by Environmental Sensitivity Registrants.....	16
3.2 Number of Hardships selected	16
3.3 Hardships by condition	17
3.4 Other areas of hardship	18
3.5 Profile of Level of Impairment, Disease Burden and Unmet needs.....	19
Section 4.0 Discussion.....	20
Section 5.0 Conclusion	23
Section 5.0 References.....	25

Section 1.0 Introduction

The results from the ANRES register shows that people with Environmental Sensitivities have a number of co-morbid diseases and have significant hardships and disabilities that occur in all aspects of their lives. These disabilities are, apart from ill health symptoms, an inability to earn an income, inability to find safe and affordable housing, inability to socialise and function in society particularly in public areas where chemicals and EMF's are prevalent.

For those with Environmental Sensitivity institutional denial and stigma have become a barrier to medical care, employment, education etc. This is a major ongoing and developing crisis for those with these conditions. These conditions lead to a reduced quality of life and often result in a loss of employment and consequent poverty, possible homelessness, isolation and exclusion from society.

The lack of consensus amongst the medical profession on the diagnostic criteria for these conditions means that many people do not have a diagnosis and so their condition/s are not included in health surveys or hospital records and therefore there is no evidence of their presence in the community. Environmental Sensitivities have far reaching implications if left undiagnosed and untreated. It not only affects the health of the individual, it also affects that person's lifestyle, family situation, financial situation, ability to socialise, ability to support oneself or family, and their ability to access and utilise facilities such as hospitals, schools, libraries, shopping centres, health care facilities etc. Add to this is the millions of dollars in lost productivity to society.

Many people are suffering hardships and continue to be ignored because there is no evidence that they exist, and there are people in the community with symptoms of these conditions who are not diagnosed and do not know what is causing their chronic ill health and continue to be exposed to triggers and develop more sensitivity.

The Australian National Register for Environmental Sensitivities (ANRES) want to show the Australian Government, employees and Health Services that there are Australians from all around the country suffering from these conditions. We need Environmental Sensitivities to be recognised as a disability and facilitate moving forward with issues such as access to medical and disability services for people with Environmental Sensitivities.

1.1 Environmental Sensitivities

Environmental Sensitivities (ES) describes a variety of reactions to chemicals, electromagnetic fields and other environmental factors at exposure levels commonly tolerated by most people. The Environmental Sensitivities included in this report are largely hidden or invisible disabilities in our society. They include Multiple Chemical Sensitivity (MCS), Chronic Fatigues Syndrome/ Myalgic Encephalomyelitis (CFS/ME), Biotoxin-related Illnesses, Lyme Disease &/Or its co-infections, Fibromyalgia, Electromagnetic Hypersensitivity (EHS), Fragrance Sensitivity and Food Sensitivities.

These conditions are 'invisible' as many people with Environmental Sensitivities are physically isolated from the community in their efforts to avoid toxic exposures and are therefore, they are out of the public eye and easier to ignore. An ASEHA survey of people with MCS found that nearly 90% of patients reported living in either a high or medium degree of isolation (ASEHA, 2011). People do not bear any visually recognisable disability markers such as wheelchairs, and there is a lack of diagnosis or

recognition by mainstream medicine and along with disbelief by the public, means that a lack of awareness of these invisible diseases often translates into disbelief.

The environmental factors that cause or trigger Environmental Sensitivities includes chemicals in cleaning products, perfumes, air fresheners, plasticisers, exhaust fumes, newspaper print and more, in the case of Chemical Sensitivities; Electromagnetic fields (EMF) emitted from mobile phones, wireless technology, smart meters etc for EHS; or mould for Biotoxin related illnesses. Environmentally Sensitive individuals can suffer various degrees of health injury and disability whilst in the built environment, including medical facilities during emergencies. The importance of the built environment and indoor air pollution has not been understood or addressed by any health or social service provider. Buildings are more tightly sealed and often have reduced ventilation rates in order to save energy costs, added to this is the use of synthetic building materials and furnishings.

1.2 Origins of Environmental Sensitivities

Genuis in 2014 explored the literature for the potential origins of chronic afflictions and multimorbidity and has found that 70% to 90% of disease is likely related to environmental determinants. An abnormal immune response might be triggered by inciting exposure such as certain foods, inhalants, chemicals and electrical incitants. (Genuis, 2014). The greater the total toxicant burden, the more severe the hypersensitivity state (Genuis & Tymchak, 2014).

According to Molot, 2013 , these conditions are Environmentally-Linked and

- The rise of these conditions is linked to wide proliferation of industrial and 'everyday' chemicals, EMF sources, mould contaminated buildings etc.
- The ability to detoxify is compromised in people with these conditions, with genetic and epigenetic factors as part of this picture.
- High levels of oxidative stress are present and require reduction through specialized avoidance strategies and specialized treatment.
- There is damage to and poor function of cellular organelles and a lack of power in the mitochondria is found.
- Systemic inflammation is common - affecting both the central nervous system and potentially other organ systems, including cardiovascular, lung, digestive, kidney and urinary tract, skin or any system in the body. Co-morbidities are common as a result of this. (Molot, 2013)

What these conditions have in common is that

- once affected they must be treated and managed over time quite often a lifetime;
- they affect the CNS and many other organs or body systems can be affected;
- as severity increases there is more co-morbidity; many people have 2 or more conditions simultaneously.

(Molot, 2013)

In Australia our exposure to chemicals present in our food, water, air has been exponentially increasing in the last few decades. There are over 113 million chemicals registered for use in

Australia with approximately 90% of the synthetic (man-made) chemicals have not been tested for their impact on human health (Bijlsma & Cohen, 2016). EHS has become a huge problem due to the widespread expansion of wireless technology and imminent 5G roll out.

Section 2.0 ANRES Data to October 2019

2.1 Environmental Sensitivity Conditions Selected

To August 2019 the ANRES website has had 310 people registering their Environmental Sensitivities. The most frequently reported condition is MCS (76.5%) closely followed by Fragrance sensitivity (76.1%) and Food sensitivity (69.7%), then CFS/ME (44.2%), EHS (43.5%), Fibromyalgia (29.7%), Lyme disease (11.0%) and Biotoxin-related illness (8.7%). See table 1 below. We do not know if this will be a general trend or if larger numbers of MCS are registering due to the spread of the ANRES project through the MCS community or it may be in part due to chemical hypersensitivity in the general community.

Environmental Sensitivity Conditions	Number	Percentage %
MCS	237	76.5
Fragrance Sensitivity	236	76.1
EHS	135	43.5
Food Sensitivity	216	69.7
CFS/ME	137	44.2
Fibromyalgia	93	29.7
Lyme Disease &/or it's co-infections	34	11.0
Biotoxin-related illness	27	8.7
Other	75	24.2

As registrants can select more than one condition, the percentages do not add up to 100%

The high number of Perfume Sensitivity registrations is not surprising as a national representative survey of over 1,000 Australians showed that one in three Australians experience health problems when exposed to common fragranced consumer products (Steinmann, 2017). In the Fitzgerald 2008 paper, of the 16% of the SA population who reported chemical hypersensitivity, 82.5% attributed perfumes as a trigger of their hypersensitivity symptoms. Perfume can trigger a range of symptoms from migraines to difficulties with breathing. Perfume is found in numerous products such as lotions, hairsprays, toothpaste, dental floss, sunscreens, diapers, laundry products and products. (Steinmann, 2018; Fitzgerald, 2008; Steinmann 2017)

Fragrances are the leading cause of allergic skin reactions in children, an Australian study published in the Australasian Journal of Dermatology revealed. "Fragrance mix allergy is increasing in children, possibly because of its increased use in cosmetics and the fact that children are using a wider range of cosmetics earlier in life," (Felmingham et al, 2019).

2.2 Other Conditions Reported

Having Environmental Sensitivities does not preclude having other medical conditions for which medical intervention or care in hospitals maybe necessary.

The Other conditions identified includes

- Allergies - skin, food and other allergies,
- Other types of sensitivities such as light, noise and motion sensitivities, dust, wood smoke, sensitivity to mould and water damaged buildings, medications sensitivity
- Respiratory conditions eg Asthma, COPD,
- Autoimmune diseases eg Hashimoto's, arthritis,
- Gastrointestinal conditions,
- Neuralgia,
- Cancers,
- Mental health issues such as anxiety disorder and PTSD as a result of having Environmental Sensitivities
- Sleeping difficulties
- Epilepsy

2.3 Number of Conditions

Many people with Environmental Sensitivities have conditions that overlap and co-exist. Those registering can select more than one Environmental Sensitivity condition. The numbers of conditions that registrants selected are represented as percentages of those reporting 1 condition to the maximum of 8 conditions. Table 2.

Table 2. Number of Environmental Sensitivity Conditions		
Conditions	Number	Percentage %
0	2	0.6
1	28	9.1
2	56	18.2
3	67	21.8
4	61	19.8
5	50	16.2
6	34	11.0
7	9	2.9
8	1	0.3

The majority of people (89.9%) have indicated that they have two or more concomitant conditions. The numbers of people selecting 1 to 4 conditions were 68.9% compared with 30.4% for 5 to 8 conditions.

The two registrants who listed other conditions only, were 1) Sensitive to sulphite preservatives – suffers headache suggesting a food sensitivity; 2) and the other sensitive to cigarette smoke triggers migraine-like headaches is also sensitive to paints and fibreglass fumes suggesting a chemical sensitivity.

Of those who registered one condition – there were 14 with EHS (4.5%); 4 with MCS (1.3%); 3 with CFS/ME (1.0%); 3 with Fragrance sensitivity (1.0%); 1 with Food sensitivity (0.3%); 1 with Lyme Disease 1 (0.3%); and 2 with Other conditions (0.6%).

2.4 Common Environmental Sensitivity Co-conditions

Our study shows that a number of Chronic Environmental Sensitivities occur concomitantly, and this is consistent with published data. Table 3. Halapy and Parlour, 2013, concluded that as the severity (*of Environmental Sensitivity conditions*) increases, there is generally more co-morbidity and many people have two or more conditions simultaneously. These conditions all exist on a gradient from mild to severe, and all produce devastating symptoms that can lead to total disability.

In 2018, a University of Melbourne study determined the prevalence of MCS in Australia. This study found 6.5% of people reported medically diagnosed MCS, 19.8% reported chemical sensitivity. Among those with MCS 74.6% also had a diagnosis of asthma and 91.5% with a fragrance sensitivity diagnosis. (Steinmann, A., 2018). Previous MCS prevalence figures for diagnosed MCS was 1 – 2.9% (Fitzgerald 2008; NSW Health, 2002) showing that there has been a substantial increase in people medically diagnosed with MCS with little change in chemical hypersensitivity (16-24% Fitzgerald, 2008; NSW Health, 2002) VS 18.9% (Steinemann, 2018)

According to Genuis 2014 the hypersensitive state magnifies, and the body responds to inciting exposures with the release of a storm of bioactive compounds, resulting in multisystem manifestations with consequent health complaints. The abnormal immune response might be triggered by inciting exposures such as certain foods, inhalants, chemicals, and electrical incitants. The reaction is often most prominent in the first 12 to 24 hours after incitant exposure and will typically settle after 3 to 5 days if not retriggered. (Genuis, 2014)

In the ANRES study we have only looked at the overlap between 2 conditions and these can be seen in Tables 3 and Figures 1. Figure 1 is a graphic representation that shows the overlap of conditions with MCS and each other.

Environmental Sensitivity Conditions	Table3 Co-conditions (percentage of those with the condition)					
	MCS	CFS	EHS	Fibromyalgia	Fragrance sensitivity	Food Sensitivity
MCS	--	(114) 48.1	(93)39.2	(75) 31.6	(213) 89.9	(186) 78.5
CFS	(114) 83.2	--	(56) 40.9	(72) 52.6	(116) 84.7	(114) 83.2
Fibromyalgia	(75) 81.5	(72) 78.3	(37) 40.2	--	(79) 85.9	(80) 87.0
Fragrance Sensitivity	(213) 90.3	(116) 49.2	(87) 36.9	(79) 33.5	--	(190) 80.5
EHS	(93) 68.9	(37) 41.5	--	(37) 27.4	(87) 64.4	(91) 67.4
Food Sensitivity	(186) 86.1	(114) 52.8	(91) 42.1	(80) 37.0	(190) 88.0	--

Table 3 Environmental Sensitivity Co-conditions continued						
Environmental Sensitivity Conditions	Table Co-conditions percentage (%) of those with the condition					
	MCS	CFS	EHS	Fibromyalgia	Fragrance sensitivity	Food Sensitivity
Lyme Disease &/or it's co-infections	(25) 73.5	(26) 76.5	(16) 47.1	(16) 47.1	(26) 76.1	(27) 79.4
Biotoxin-related illness	(25) 92.6	(18) 66.7	(16) 59.3	(14) 51.9	(21) 77.8	(17) 63.0

An overlap between all of the conditions are evident. In Figure 1 and Table 3 we can see that there seems to be a significant relationship/overlap between MCS and the other conditions. A sensitivity to chemicals, especially those in fragrance and food, is a common in all conditions. The overlap between Biotoxin-related illness and MCS is not surprising as mould sensitivity has been listed as a common trigger in MCS. Inflammation appears to be a key process in these conditions. A 2011 survey of people with MCS found that most respondents (88%) reported having prior allergic &/or non-allergic inflammatory conditions. (ASEHA,2011). These results suggest a common process such as immune sensitisation.

Which condition develops first seems to depend on an individual's situation and what they were predominately exposed to initially e.g. a registrant commented that *"a Wet Damaged Building (WDB) causing me biotoxin poisoning from mould/fungus. This triggered Chemical and Electrical Hypersensitivity in me"*. For others it was CFS/ME may have developed first, or MCS from chemical exposures, or EHS following installation of Smart Meters etc.

Figure 1 Overlap between MCS and other Environmental Sensitivity Conditions

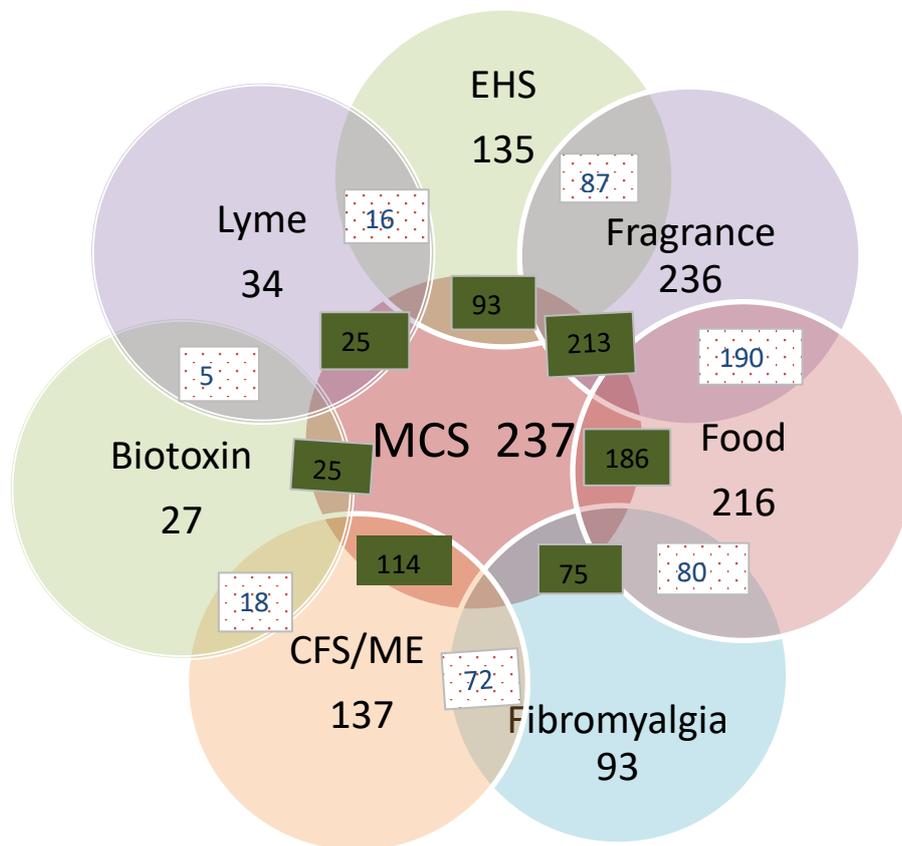


Figure 1. The coloured circles represent the Environmental Sensitivity condition and the numbers selecting each.

The numbers in the solid green text boxes represent the overlap with MCS

The numbers in the red dotted text boxes are the numbers overlapping each condition

2.5 Characteristics of people with Environmental Sensitivities

2.5.1 Conditions by Gender

The number of Females registered is 83.2 % (258), compared to 16.8 % Males (52). We are consistently seeing 5X more females (83%) than males (17%) registering environmental sensitivities.

These numbers are consistent with overseas estimates of 80% in women compared to 20% in men (Caress and Steinmann, 2003; NSW Public Health 2002; Fitzgerald, 2008) with women reporting more severe symptoms [Joffres et al, 2001]. The South Australian survey of MCS and chemical hypersensitivity also showed that 90% of females compared to 66% of males report perfumes etc as a chemical trigger of hypersensitivity (Fitzgerald, 2008).

When determining the various conditions and gender in the ANRES register, EHS is the only condition where more males are represented more than females, 51.9% males vs 41.9% females respectively. Females reported more MCS, Fragrance Sensitivity, Food Sensitivity and Fibromyalgia. The percentages are similar for Lyme Disease, Biotoxin-related illness, CFS/ME and other conditions. Table 4.

Environmental Sensitivity Conditions	Males (n=52)		Female (n=258)	
	Number	Percentage of males (%)	Number	Percentage of females (%)
MCS	31	59.6	206	79.8
Fragrance Sensitivity	29	55.8	207	80.2
EHS	27	51.9	108	41.9
Food Sensitivity	30	58.8	186	72.1
CFS/ME	20	38.5	117	45.3
Fibromyalgia	10	19.6	82	31.8
Lyme Disease &/or it's co-infections	6	11.5	28	10.9
Biotoxin-related illness	3	5.8	24	9.3
Other	13	25.0	62	24.0

As registrants can select more than one condition, the percentages do not add up to 100%

2.52 Number of Environmental Conditions by gender

Number of Conditions	Males N=52	Percentage Of males	Female N=258	Percentage of females
1	9	17.3%	19	7.5%
2	12	23.1%	44	17.1%
3	11	21.2%	56	21.7%
4	7	13.5%	54	20.9%
5	6	11.5%	44	17.1%
6	5	9.6%	28	11.2%
7	0	0.0%	9	3.5%
8	0	0.0%	1	0.4%
1-3 conditions	32	61.5%	119	46.1%
4-8 conditions	18	34.6 %	137	53.1%

In this survey Males with 1-3 conditions 61.5% and 4-8 conditions 34.6% while females with 1-3 conditions 46.1% and 4-8 conditions 53.1%.

Burstyn and MEAO, 2013, found that while men and boys do suffer from Environmental Sensitivity conditions, they noted that more women are affected by the three conditions in their study than men. This is similar to ANRES results where more females (53.1%) than males (34.6%) have more than three conditions. Table 5

According to Dr Molot a common denominator of the three conditions is their study (MCS, CFS/ME and Fibromyalgia) is limbic system sensitisation and there are gender differences in how the limbic system responds. Different limbic structures are activated between men and women following the same proactive stimuli. The enzyme systems for detoxification are more active in women than men, and women retain more inhaled volatile organic compounds than men. Women also generally have higher domestic responsibilities than men and use more cosmetics, sin care and scented products (Molot, 2013)

In summary, Molot found that the prevalence of environmentally linked illnesses are more common in women because they are more responsive to their environment via both the limbic and immune systems, have a greater body burden of chemical exposures and less efficient detoxification systems compared to men. (Molot, 2013)

2.53 Onset and duration of conditions

Environmental sensitivities can develop at any age, (Shannon et al 2003; Woolf, 2000) and increase with age (Sears, 2007). The increasing in prevalence of sensitivities is relevant for young children just starting their life in society, young professionals in the prime of their working careers, the aging workforce, as well as care for the elderly. For children Environmental Sensitivities can have negative consequences on education, their physical and emotional health, earning potential and overall wellbeing later in life. As these conditions often develops in middle age this is during a time when they are potentially at their peak earning potential and contributing most to the economy.

The elderly are very disadvantaged by Environmental Sensitivities (ES). They have managed to care for themselves most of their lives and as they age, the chronic relapsing nature of Environmental

Sensitivity conditions such as Multiple Chemical Sensitivities, Electromagnetic Hypersensitivity and co-existing diseases places them at great disadvantage. In many cases people with Environmental Sensitivities are financially crippled and maybe existing on a pension which does not allow them to purchase the medical aids, nutrient supplements and assistance they need to survive with any quality of life.

Age when Environmental Sensitivities developed

The average age that people have developed these sensitivities in the ANRES survey is 36.5years, Table 6. with a minimum age at birth to a maximum age of 76 years. The age group affected in this register is like that in the Halapy and Parlour OCEEH report, 2013 where the majority of those affected are the ages 45-64. (Halapy and Parlour OCEEH, 2013)

Those people who commented that they felt they were born with it, is perhaps suggesting a genetic component and an exposure or event 'tipped' them over the edge.

Table 6. Age when developed Environmental Sensitivities		
Age when developed	Number	Percentage (%)
0-10	19	7.0
10-20	21	7.4
20-30	61	22.3
30-40	61	22.3
40-50	65	23.8
50-60	37	13.6
60+	9	3.3

Ave 36.5, min 0, max76; mode 41. The Mode is the most frequently occurring number.

Conditions such as food intolerances, chemical sensitivities, fragrance sensitivities were reported to have started in childhood. Offspring of people with Environmental Sensitivities are beginning to experience similar health problems such as food and environmental chemical sensitivity suggesting a genetic component.

Duration (years) with the Condition/s

These conditions are chronic as can be seen in Table 7., the majority of people registered on this site have had their condition/s for greater than 16 years (44.7%). Table 7

Table 7. Duration (years) with the Conditions/s		
Duration with the Condition/s	Number	Percentage (%)
1-5	41	14.9
6-10 years	73	26.5
11-15 years	37	13.5
16+	123	44.7

Ave 18.9; min 1 year; max 78; mode 6. The Mode is the most frequently occurring number.

There are many people who have been dealing with these conditions for 16+ years (44.7%). This suggests that many became afflicted during their most productive work and family years. Many of

these people are now coming into older age where they, may need increased medical care, potential hospital stays and possibility of requiring aged care residence.

Current Age Groups of Registrants

Age group	Number	Percentage (%)
0-15	6	2.0
16-30	12	3.9
31-45	63	20.4
46-60	117	37.9
61+	111	36.4

Ave 54, Min 9 and max 94. Mode 56

The majority of people who have registered on the ANRES website are > 46 years. These people will be looking to try and navigate older age over the next 10 – 20 years with conditions not catered for by mainstream medicine.

All age groups are represented in this study and this is consistent with published data. The largest age group of registrations have come from the 45-60 age group, people who are in their most productive years with ongoing careers, house payments and children at school all of which requires a steady reliable income. Table 8

2.54 Diagnosis:

The reported onset of Environmental Sensitivities and the diagnosis of conditions noted in this register are variable.

- A number have been diagnosed with different conditions as they are progressively recognised. Overall 226 (72.9%) have been diagnosed with one or more conditions while 84 (27.1%) have not been given a diagnosis. Some medical practitioners and specialists will treat people for conditions such as migraines or autoimmune conditions without diagnosing these conditions as MCS, biotoxin related illness or EHS
- Part Diagnosis is common, they may be diagnosed for one condition such as MCS or CFS, but not for any other of the conditions they have symptoms of such as EHS. Others have self-diagnosed environmental sensitivities but may have a diagnosis of allergies and asthma..
- There are many for whom the symptoms of conditions developed many years before any formal diagnosis was made, for some it took 25 years for any sort of diagnosis. This is similar to overseas data where several years elapsed before they received a diagnosis. For greater than 50% of the respondents it took 4 or more years and for 19% it took greater than 10 years (Halapy and Parlour, 2013).
- There are people who have found that alternative therapies help, and others have by necessity researched their condition to find a diagnosis and means to improve their lives. This trend is consistent with the Halapy and Parlour OCEEH report, 2013, where their data suggested that people are looking for effective care and therapies outside of conventional medicine (Halapy and Parlour, 2013).
- Many people are unable to attend General Practitioners and physicians who specialise in Environmental Sensitivities for a diagnosis for a number of reasons

- lack of knowledgeable physicians,
- distance required to travel to doctors
- the cost of consultations that do not attract medicare rebates and
- physical barriers due to the medical practice use of air fresheners, staff wearing perfumes, new carpets, photocopier voc's, emf from wi-fi etc.

A delay in diagnosis can mean a worsening of people's original conditions that may lead to development of other chronic conditions or sensitivities. Some of the specific interventions recommended by physicians included chemical avoidance as a primary measure, alterations in the home environment, diet restrictions, or air purifiers in the home.

Currently these conditions are diagnosed based on exclusion as they have no clear aetiology, evidence-based guidelines, pathogenesis or genetic or metabolic markers. There seems to be a common mechanism of neurological sensitisation and damage to the defence mechanism against environmental agents.

Bijlsma and Cohen 2018 in a paper on "Expert clinician's perspectives on Environmental medicine in Australia" investigated environmental clinicians opinions on Environmental Sensitivities and identified 5 dominant themes from their interviews.

1. Environmental Medicine is a divided profession between Integrative clinicians (IP's) and Occupational Medicine and Environmental Physicians (OEP).
2. Clinical assessment of toxicant exposures is challenging requiring longer consultation times and no definitive laboratory tests
3. The environmental exposure history is the most important clinical tool
4. Patients with environmental sensitivities are increasing, often have unique phenotypes, present with allergies (foods and aeroallergens), neurodevelopment and mould-related disorders, are complex to treat and rarely regain full health. Patients with environmental intolerances such as CFS, MCS, EHS, fibromyalgia and sick building syndrome are complex to diagnose, complex to treat, and rarely regain full health.
5. Educational and clinical resources on Environmental Medicine in Australia are lacking. Toxicant exposure assessment requiring complex areas such as genetics, nutrition and microbiomics are not taught or used/integrated into clinical practice. (Bijlsma and Cohen 2018).

Overall Environmental Medicine clinicians felt that educational and clinical resources on Environmental Medicine are lacking in Australia. (Bijlsma and Cohen 2018). This is reflected in overseas papers, where a 2011 US study found that only 30 % of doctors receive formal training about MCS (Gibson & Linderberg, 2011). In the MEAO study a lack of education and training seen as responsible for negativity, discrimination and neglect. (Burstyn and MEAO 2013)

Section 3.0 Burdens/Hardships experienced by those with Chronic Environmental Sensitivities

We can see from the ANRES register results that Environmental Sensitivity conditions are chronic and require lifelong management of their environment, health, work place etc. In 2013 Burstyn and MEAO report looked at the level of disability in Environmental Sensitivity Conditions compared them with the more well-known chronic conditions such as cardiovascular disease, diabetes, respiratory conditions etc. They found that the conditions MCS, CFS and Fibromyalgia were at least as disabled and, in some cases, more disabled than other chronic conditions. The results of this comparison showed that the levels of unmet health care needs or home care services indicate the Environmental Sensitivities are receiving ineffective care or experiencing barriers to or defects in care. People with these conditions are experiencing socioeconomic disadvantage as demonstrated by high levels of moderate or severe food insecurity and sizeable proportions with low annual household income” (Burstyn and MEAO, 2013).

Gibson et al stated in a 2014 paper that *‘We ... planned to focus on the impact of MCS on relationships but found that difficulty with accessing safe spaces at times prevented relationships by limiting access to personal interactions. Thus, persons with MCS either lost or were unable to cultivate new relationships as a result of lack of spatial access. Others’ lack of understanding and refusal to make accommodations at times denied spatial access to those with MCS. In this way, relationships (relationality) and spatial access (spatiality) interacted with one another to keep persons isolated.’* (Gibson et al, 2014) This seems to be the case for other Environmental Sensitivities.

A consistent pattern in relation to all the Environmental Sensitivities covered in this register has emerged across a variety of factors related to disability, socioeconomic status, health care utilisation and unmet health care needs. These factors can significantly affect families, caregivers, work colleges, employers.

In health care there is a lack of knowledge about such conditions and an inability to diagnose or treat correctly. This results in neglect or iatrogenesis, lack of compassion and respect and persistent widespread stigmatisation of the patient as either emotionally disturbed or hypochondriac or both. Physicians are gatekeepers and legitimisers within society.

3.1 Hardship Categories selected by Environmental Sensitivity Registrants

All of these conditions exist on a gradient from mild to severe, all produce devastating symptoms that can lead to total disability. Table 9

Table 9. Hardships selected		
Hardship	Number	Percent
Medical assistance	165	72.7
Housing	124	54.6
Education	89	39.2
Employment/Income	178	78.4
Social Services	88	38.8
Accessing public places	147	64.8
Relationships/social interactions	199	87.7
Other	75	33.0

The number of people answering hardship question n=231

The areas people are finding most problematic are as seen in Table 9 are

1. Relationships/Social interactions (87.7%) due to people use of fragranced products, mobile phones, ill health or lack of understanding
2. Employment/Income (78.4%) due to fragrance use, EMF, mouldy buildings, ill health, lack of understanding
3. Medical assistance (72.7%) due to fragrance use, mobile phones/EMF sources, ill health, lack of understanding or costs
4. Accessing public places (64.8%) due to people use of fragranced products, mobile phones or lack of understanding
5. Finding adequate Housing (54.6%) free from chemicals or EMF sources
6. Education (39.2%)
7. Social services 38.8%
8. Other factors such as travel and home maintenance (33.0%).

3.2 Number of Hardships selected

These hardships cover all aspects of a person's life and would be not occur for others not suffering from Environmental Sensitivities. 82.3% of people who have registered with ANRES live with 3 or more hardships because of their illness/s. Table 10

Table 10 Number of hardships		
Number of hardships	Number	%
1	16	6.9
2	19	8.2
3	33	14.3
4	36	15.6
5	37	16.0
6	34	14.7
7	27	11.7
8	23	10.0

3.3 Hardships by condition

Table 11 Hardship selected by conditions					
Hardship	MCS % n=171	EHS/ES % n=95	CFS/ME % n=105	Fragrance Sensitivity % n=171	Fibromyalgia % n=76
Medical assistance	77.0%	72.4%	79.4%	74.1%	79.2%
Housing	60.3%	62.2%	48.6%	55.2%	51.9%
Education	37.9%	49.0%	36.4%	38.8%	40.3%
Employment/Income	81.0%	77.6%	79.4%	79.9%	77.9%
Social Services	42.5%	43.9%	35.5%	42.0%	45.5%
Accessing public places	69.5%	68.4%	67.3%	70.7%	66.2%
Relationships/Social Interactions	90.2%	90.8%	91.6%	87.9%	93.5%
Other	33.3%	39.8%	34.6%	34.5%	32.5%

Table 11 cont. Hardship selected by conditions			
Hardship	Biotoxin n=23	Lyme disease n=25	Food Sensitivity n=163
Medical assistance	87.0%	92.0%	73.0%
Housing	73.9%	48.0%	54.6%
Education	43.5%	40.0%	39.9%
Employment/Income	91.3%	88.0%	79.1%
Social Services	56.5%	52.0%	40.5%
Accessing public places	56.5%	60.0%	68.7%
Relationships/Social Interactions	95.7%	72.0%	90.2%
Other	47.8%	24.0%	32.5%

The ANRES registered Environmental Sensitivity conditions all have difficulty with all Hardship categories. For all conditions the percentage suffering hardships with relationships and/or social interaction are highest. This is mainly due to the ubiquitous use of fragranced products or EMF emitting devices. Table 11

Those with MCS, Fragrance Sensitivity and EHS were the most impacted in their ability to access medical assistance, accessing public places, Employment and Relationships/Social Interactions.

Fragrance Sensitivity and MCS registrants show the highest percentages for all hardships. The percentage of hardships for Fragrance Sensitivity and MCS are - relationships/social interaction (64.9% and 68.4% respectively), followed by Employment/income and Medical assistance (57.9% and 57.0% respectively) for Fragrance Sensitivity and 58.8% and 57.9% respectively for MCS. This is not surprising considering the ubiquitous use of fragranced cleaning chemicals, perfumes, pesticides etc that are barriers and create hardships.

3.4 Other areas of hardship

People registering were able to comment on other areas that they have had difficulties with. These are basically an extension to the hardship categories.

<p>Travel: Public transport/travel including flying; or Needing to contact any accommodation providers to ensure room chemical free;</p>	<p>Having to treat (wash) new clothing before wearing; Paying bills in person; Personal care (eg haircut);</p>	<p>Severe curtailment of activities</p>
<p>Medical: Medical Assistance from hospitals for health care or visiting people in hospital, visiting relatives in Aged Care, Medical Health Facilities centres, allied health care such as dental or physiotherapy; lack of Treatment</p>	<p>Public areas:</p> <p>Eating out/Restaurants; Public conveniences; wi-fi and mobile phone exposure in public spaces; outdoor markets are full wireless transmissions from cell phones, cell phone tower and etpos;</p>	<p>Accessing child school activities engaging in their education;</p> <p>Social isolation – from interaction at restaurants etc, holidays, public, medical staff, family and friends; Loneliness and stress from lack of understanding</p>
<p>Chronic pain;</p>	<p>Sporting fields - masts or people with mobiles;</p>	<p>Accessing places of worship due to fragrance;</p>
<p>Mental health problem dealing with their situation, depression, anxiety, PTSD;</p>	<p>cinema, community events and organisations;</p>	<p>Unable to live a normal life;</p>
<p>Home Maintenance: Physical difficulty with housework, gardening, day-to-day activities</p>	<p>Recreational activities/hobbies;</p>	<p>Employment/Financial: Workplace discrimination, unemployment; Homeless and debt;</p>
<p>Tradespeople may wear fragranced products or carry mobile phones;</p>	<p>Community events; Creative projects such as art exhibiting, music teaching & performance;</p>	<p>Lack of Access to NDIS;</p>
<p>Shopping/Personal Care: Finding suitable clothing;</p>	<p>Life Disruption:</p>	<p>Financial cost to maintain health – air filters, water filters, immune system supplements, organically grown food, non-standard medical expenses not covered by Medicare;</p>

Air flight difficulty is unsurprising as an online article by Bearnairdine Beaumont entitled 'What toxins are we being exposed to in air travel?' States that *"Along with organophosphates that are added as a lubricant to aircraft engine oil, over 120 other toxic substances including insecticides and flame retardants, have been detected by EASA, the European Air Safety Agency. This chemical cocktail can create what has been described as 'aerotoxic syndrome' following exposure – a set of health conditions people have suffered that have been linked to toxins in air cabins."* (Beaumont, 2019)

Accessing Public Places due to fragrance is not surprising as a press release issued from the American Chemical Society in 2018 talked of Making Fragrances last longer. The 'problem' for the fragrance industry was that a lot of fragrance oils in fragranced products such as face washes & body scrubs get washed away. Company researchers looked to 'amplify the efficacy, add to the allure and ensure the integrity of the retention of fragrances notes in the products for skin and hair'. This has been achieved with the addition of polymers to fragrance, each different type of fragrance with its different combination of scents (trade secrets) requiring a particular polymer. (ACS, 2018). This makes it nearly impossible to access public places or be close to others in the community or remove fragrance from clothes, pillows, couches etc.

3.5 Profile of Level of Impairment. Disease Burden and Unmet needs

The results of the ANRES data on the effects/life impacts of Environmental Sensitivities show that these conditions are pervasive and include

- Damage to income and work resulting in joblessness and financial destitution, leading to problems with affordable housing, or being able to make modification to existing home, resulting in some facing homelessness and destitution;
- Financial cost for non-medical expenses air filters, water filters, immune supplements, organic food
- Difficulty with access to medical care and community resources. There may be problems with finding a doctor who understands sensitivities or finding safe medical facilities.
- There are problems with relationships and lessened social support. There are difficulties meeting with other people (professionally and personally) because of others personal use of fragrances, use of a mobile phone or because of stigmatisation by others who do not understand or believe these conditions;
- There can be diminishing relationships and social interactions for the whole family. These individuals and their families can be living in social exclusion and economic difficulties. This impacts on wellbeing, family life, friendships and social integration
- Limited to no access to public places such as restaurants, hospitals, libraries, shopping complexes, education facilities, recreation facilities etc.
- Inability to study at schools, universities or other institutions due to fragrance use and the expansion of wi-fi and EMF sources
- There can be debilitating symptoms, some people are largely bed ridden, many are home bound and isolated from friends, family and society.

- In severe cases every area of life is compromised with public life becoming extremely limiting and social isolation becomes the norm. From one registrant *“I am well at home, and always ill when I leave the house for any little thing. Consequently, I am home most of the time.”*

These results reflect the burden impacts found in other studies. The ASEQ-EHAQ (The Environmental Health Association of Quebec) have also heard distressing stories from their members who when they have accessed health care have become sicker because of chemical substances present in hospitals or clinics. Many avoid trying to access health-care facilities even when there is a dire need in order to avoid chemical substances. They also found that synthetic fragrances are a barrier to receive health care. Fragrances have detrimental effects not only for people with Environmental Sensitivities but also for those who suffer from asthma and other respiratory conditions, migraines, and skin conditions such as dermatitis. (ASEQ-EHCA, 2019)

The ANRES registrant results show that people’s rights to medical care, the right to earn an income, access to affordable and safe housing, access to an education and access to public places are denied to them because of their conditions, placing an added strain on an already difficult and disabling medical conditions. The resultant impacts of these conditions are far reaching and significantly affects families/caregivers, communities and society.

Section 4.0 Discussion

Physicians with experience with environmental sensitivities claim that diagnosing and treating environmental sensitivities early often stops the illness in its tracks (Kassirer and Sandiford, 2000; Genuis and Lipp, 2011; Genuis and Tymchak, 2014). Dr G H Ross of the Environmental Health Centre, Nova Scotia, Canada, a specialist in diagnosing and treating Environmental Sensitivities claims the chronic cases he sees are the result of the failure to diagnose and properly treat environmental sensitivities (Kassirer and Sandiford. 2000). Environmental Sensitivities need to be included in the medical course curriculum and Continuing Medical Education (CME) process to ensure that all physicians are educated in how to diagnose and manage Environmental Sensitivities.

The basis of treatment needs to be

- Recognition of potential or actual triggers, (by taking a history of exposures in the community, home, hobbies, occupation, personal exposures, diet and medications)
- Once triggers are identified to then reduce or eliminate the sources
- Optimise an organic diet free from additives, colours etc
- Address any nutritional deficiencies such as vitamins and minerals
- If possible, identify the body burden of toxins such as heavy metals or chlorinated compounds

The Medical profession can greatly assist people with Environmental Sensitivities with letters of support rather than medications to which many people with Environmental Sensitivities are sensitive. The use of antidepressants and other psychoactive medications to treat SRI might

exacerbate the problem due to inefficient bioelimination adding to their toxicant burden. (Genuis, 2014)

These Letters or paperwork provided by physicians can assist with social welfare services are for example In-home support, Carers, Unemployment benefits, Sickness benefits, Disability support, Compensation payments for workplace injury, Referral to specialists, physiotherapists and OTs etc .

Health services can help by modifying their rooms to avoid triggers. Restricting the use of fragranced products can help more people than those with Environmental Sensitivities. The Steinmann, 2017 study found that the common adverse effects of fragranced products included respiratory problems, mucosal symptoms, asthma attacks, migraine headaches amongst others. (Steinmann, 2017).

Environmental Sensitivity conditions are largely misunderstood by medical practitioners and the general community and this means that for people with ES their basic medical and social needs go unmet. Environmental Sensitive patients may have other health issues that require specialist care or other types of medical intervention. Because of this lack of understanding people are constantly being made ill when trying to access services or a workplace.

They affect people's ability to function normally in society. While many chronic disabling conditions are known to be associated with older age (eg cancer, heart disease and stroke) Environmental Sensitivity conditions are common amongst the middle aged i.e. when they have potential to be highly productive, employable and contribute to the economy and society.

The high association of fragrance sensitivity with many of the conditions, has meant that access to many public buildings is difficult due to the high usage of perfumed products such as cleaning products, personal care products and similar. This happens in public buildings such as medical facilities, hospitals and educational facilities. Fragrance has become the new second-hand smoke problem and needs to be addressed by government and health care agencies to reduce their usage.

The Canadian Medical Association Journal, in 2015 says, "Artificial scents have no place in our hospitals", about 30% of people report having some sensitivity to perfumes worn by others, 27% of people with asthma their condition is aggravated by artificial scents, particularly concerning for hospitals patients with asthma or other upper airway or skin sensitivities are concentrated. "We have much to learn about the mechanisms underlying scent sensitivity, but we know enough now to take precautionary measures in our hospitals." Their recommendation - "Hospital environment free from artificial scents should become a uniform policy, promoting the safety of patients, staff and visitors alike." (Flegel and Martin, 2015). They note that for those with asthma there are a range of irritants that are not categorized as allergens, such as secondhand cigarette smoke, cleaning fluids (bleach), perfumes and other strong odors. This precautionary measure should also be extended to other health facilities and aged care facilities. The US Centers for Disease Control and Prevention, Indoor Air Quality Policy (CDC, 2009) states that "Scented or fragranced products are prohibited at all times in all interior space owned or leased". (CDC, 2009)

An Australian paper on the health and societal effects from exposure to fragrance consumer products found that of the 33% reporting health problems when exposed to fragranced products, "more than half (17.1%) of these could be considered disability under the Australian Disability

Discrimination Act” and fragranced products were found to hinder access to public places such as restrooms and businesses (Steinmann, 2017).

Research published in 2019 has found that is also the case internationally with 1 in 3 adults experience health problems caused by exposure to fragranced products such as perfumes, cosmetics, laundry detergents and soaps. Fragrance sensitivity causing migraines, watery eyes and respiratory issues. The results have been found in the UK, the US, Australia and Sweden . The author Professor Anne Steinmann has characterised fragrance sensitivity as a healthcare epidemic of which we don't yet know the scale. (Steinmann, 2019)

Airports in Helsinki, Vancouver and Copenhagen are recognising the problem offering perfume-free routes for passengers with fragrance sensitivity. The need for fragrance free public spaces has been recognised in Halifax, Nova Scotia with most hospitals and schools banning employee from wearing perfumes. In Oakland California city officials are asking residents to be fragrance free for public meetings.

The high usage of products such as cleaning fluids and co-workers' perfume, new carpet or photocopier fumes, or wi-fi technology and mobile phones can make the workplace a dangerous place to work. If an employer does not understand and take measures to ensure a safe workplace people are forced from their jobs or risk further health problems. Employees can assist by modifications to the workplace and consideration by both the employees and co-workers that will allow people to be productive and self-sufficient. More tightly sealed buildings reduce ventilation rates to save energy and the use of synthetic building materials and furnishings means that the IAQ is poor.

Social support is critical for those with chronic health conditions. Individuals with lower levels of social support are known to suffer more symptoms and greater mortality while a higher level of support indicates better psychological wellbeing. Individuals with MCS scored lower than healthy people and some with diabetes and multiple sclerosis (Gibson. 2014). As with other forms of chronic illness, Environmentally Sensitive patients have difficulty maintaining social contact due to pain and functional disturbances. Social Services can assist by understanding the problems and providing for example Home Care staff without wearing perfume or using fragranced and switching off their mobile phones.

Income support from welfare services is insufficient to provide for their special needs in housing, disability aids, or medical aids etc. Food and nutrient support is often required as food allergy/intolerance is often a coexisting factor along with inability to take many medications. There are many who have lost their income, do not qualify for Disability Support pensions and cannot afford Air filters, water filters, organic food that they need and their condition prolonged and worsened.

These conditions are chronic, we have found that most people registering with ANRES have had their condition/s for greater than 10 years. According to the Australian Government department of Australian Institute of Health and Welfare (AIHW) 2018 Report *“Chronic conditions are generally characterised by their long-lasting and persistent effects. Once present, they often persist throughout*

a person's life, so there is generally a need for long-term management by individuals and health professionals." This also describes Environmental Sensitivities conditions.

Whereas the common chronic disease rate is higher in people aged 65 and over (87%) in the AIHW 2018 report (AIHW, 2018) in the ANRES register of Environmental Sensitivities the average age that people developed their condition/s is 39. (AIHW, 2018)

The AIHW define "Chronic condition comorbidity (or multimorbidity) as the presence of two or more chronic conditions at the same time. Around 1 in 4 (23%) Australians had two or more chronic conditions in 2014–15 (ABS 2015)." Here the AIHW is talking about the most common chronic conditions for which mainstream medicine has a definition, diagnosis and treatment including cardiovascular disease, cancer, chronic respiratory conditions, chronic musculoskeletal conditions, diabetes and mental health problems. (AIHW 2018) Significant health care dollars are being spent to address these problems.

These definitions also describe Environmental Sensitives, but they are currently not being recognised by government and medical surveys. And therefore, despite high rates of unmet health need and disability there is no focus on research to be able to diagnose, treat, manage and perhaps prevent these conditions.

As with other forms of chronic illness, Environmentally Sensitive people have difficulty maintaining social contact due to pain and functional disturbances. Health services staff can assist by understanding the problems and provide care without wearing fragranced products and switching off mobile phones.

The AIHW latest report found that people with disabilities suffer poorer outcomes in areas such as mental and physical health, employment outcomes and education. People with disability are four times more likely to experience high psychological distress than other Australians, according to new research from (AIHW, 2018). A People with Disability Australia (PWDA) report on a survey of 900 people with disabilities found that a majority (61 percent) of people were unable to access the support they need, while 77 percent have experienced discrimination because of their disability. (Michael L, 2019)

Section 5.0 Conclusion

A consistent pattern in relation to the Environmental Sensitivities has clearly emerged across a variety of factors related to measures of disability, socioeconomic status, health care utilization and unmet health care needs. These conditions affect all ages, from the very young to the elderly and disrupts all aspects of a person's life. People are feeling alone, isolated and unable to do anything about it. These factors also significantly affect families and caregivers.

The difficult physical and emotional challenges of day-to-day life have become the new norm for people with Environmental Sensitivities. The life impacts of Environmental Sensitivities show that these conditions are pervasive and include damage to income and work resulting in joblessness and financial destitution; potential homelessness, problems with relationships and lessened social

support; access to medical care and community resources. These individuals and their families often live in social exclusion and economic difficulties.

The negative health care aspects registrants commented on includes a lack of knowledge about the condition and an inability to diagnose or treat correctly. This is resulting in neglect or iatrogenesis, lack of compassion and respect leading to persistent widespread stigmatisation of these patients as either emotionally disturbed or hypochondriac or both. Physicians are the gatekeepers and legitimisers within our society.

Misdiagnosis is common, physicians don't have any training or clinical experience, there are no definitive clinical guidelines for these conditions and vital treatment and services are not available. The depression felt by people does not equal psychogenesis it is the consequence of the devastating impact of the conditions/s and its symptoms. It can be a by-product of living with Environmental Sensitivities. Life becomes overwhelmingly difficult and demoralising.

The results of this analysis show that it is time for the medical profession, workplaces and society at large to start paying attention to those with Environmental Sensitivities. People with these conditions face challenges in their experiences such as trying to obtain a diagnosis and treatment to living with the long-term impacts of a chronic condition. Environmental Sensitivity individuals suffer from stigmatisation in clinical settings, the workplace and other areas of their lives as a result of general lack of understanding of these complex conditions by the medical profession and wider community.

While waiting for the controversy over Environmental Sensitivity diagnostic criteria to be decided and acceptance into mainstream medicine, people are suffering and will continue to suffer hardship and ill health. Early recognition, clean air, food and water and avoidance of symptom-triggering agents and modification of their homes are necessary for people to successfully live with their condition. The prognosis for Environmental Sensitivities patients is variable but many can improve in the course of time, especially with an appropriate management plan. People with Environmental Sensitivities want to be heard, believed, respected and given a fair go.

Interventions required include Government Housing suitable for Environmentally Sensitive patients, Home schooling, Disability parking, Assistance with medical aids e.g. wheelchair, oxygen at home, Aged care or respite services, Pain management services, Chronic illness/loss/grief counselling, Social workers, Rehabilitation, and Ambulance transport services.

To improve care for people with Environmental Sensitivities, the health care system needs research that would help to

- Identify the underlying cause/s of these conditions
- Understand the physical, mental, economic and social impacts
- Guide clinical practice
- Improve treatment and support

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