Measures Taken by European Countries for Multiple Chemical Sensitivity

A Danish Health Ministry Report on Enquiries of 11 European Governments

English Translation

by

Harry Clark

with

Charlotte Anker
Martine Bechmann
Mervi Herrala
Sandra Johansen
Monika Senior

Translation © 2010 MCS Society of Australia

Measures Taken by European Countries for Multiple Chemical Sensitivity

A Danish Health Ministry Report
on Enquiries Made of 11 European Governments

English Translation

by

Harry Clark

with

Charlotte Anker
Martine Bechmann
Mervi Herrala
Sandra Johansen
Monika Senior

Translation © June **2010 MCS Society of Australia Inc**MCS-Society-of-Australia@bigpond.net.au

Editor's Forward

This translation represents, as accurately as I am able, the information of the original Danish text.

This document provides baseline information on the standing of MCS within the Health Ministries of 11 European Governments (as reported by the Danish Health Ministry). This provides a valuable and unprecedented insight that may help considerably in directing efforts to gain better recognition of MCS.

The translation has been a co-operative exercise involving people from opposite ends of the Earth, from Denmark and Australia. Even in Australia the translators live over 1000km apart. Each of the six members of the translation effort have contributed valuable insights that have elevated the translation to be more accurate, clearer and easier to read.

I welcome constructive suggestions for improvements to the translation (send to MCS Society of Australia, <u>mcs-society-of-australia@bigpond.net.au</u>).

Editorial Notes

I have used the device of [square brackets] to insert editorial notes in the text. Most often the note will be the original Danish text for a preceding word, phrase or name. I have done this where I think it will aid understanding.

Cover Design:

Cover design by Harry Clark (free to share or remix for non-commercial use, with attribution). The "Smoke" image was adapted for the cover design.

Original "Smoke" image by Steve Wampler (c) (free to share or remix for non-commercial use, with attribution)
http://www.flickr.com/photos/sgw/2223880375/

Contents

C	over Note Attached to the Danish Report	. iv	
Λ	Measures Taken by European Countries for Multiple Chemical Sensitivity.1		
	Introduction	2	
	Conclusion:	3	
Each Individual Country's Responses to the Questions:		4	
	I) Belgium	4	
	II) Finland	4	
	III) France	5	
	IV) Italy	6	
	V) Luxembourg	7	
	VI) The Netherlands	7	
	VII) Spain	8	
	VIII) Britain	8	
	IX) Sweden	9	
	X) Germany	11	
	XI) Austria	13	

Cover Note Attached to the Danish Report¹



To the Health Committee,

In response on December 2009 to question No. 102 (ordinary share) of 5 November 2009 the then Health Minister signalled that the Ministry would seek information from other European countries as to whether they have introduced protective measures against MCS.

Subsequently, a memo was sent requesting information from other European countries as to their possible safeguards relating to MCS. The report has been prepared on the basis of information obtained from 11 other European countries that Denmark usually compares itself.

Haarder / Steen Hartvig Hansen

Slotsholmsgade 10-12 DK-1216 Copenhagen K Tel. +45 7226 9000 Fax. +45 7226 9001 Email sum@sum.dk Website www.sum.dk

25 March 2010 Center for Health and Psychiatry J.nr. 0908926

Sagsbeh.: SHH

¹ Original note can be found on the Danish Parliamentary site http://www.ft.dk/samling/20091/almdel/suu/bilag/285/818826/index.htm

Measures Taken by **European Countries for** Multiple Chemical Sensitivity²

[Andre europæiske lands foranstaltninger mod duft- og kemikalieover-følsomhed]



Danish Parliament

[Sundhedsudvalget 2009-10] Health Committee, 2009-10

SUU general. part 285 Appendix [SUU alm. del Bilag 285]

Public [Offentligt]

Interior and Health Ministry [Indenrigs- og Sundhedsministeriet]

Date: 24 March 2010 [Dato: 24. Marts 2010]

File No: 0908926 [Sags nr.: 0908926]

Caseworker.: SUMSHH / [Sagsbeh.:SUMSHH /

Center of Health and Psychiatry Center for sundhed og psykiatri]

Doc No: 191269 [Dok nr.: 191269]

² Original Danish language document can be found on the Danish Parliamentary site http://www.ft.dk/samling/20091/almdel/suu/bilag/285/818825/index.htm

Introduction

In the reply of 21 December 2009 to question no. 102 (General part) [(alm. del)] from the Health Committee [Sundhedsudvalget], the former Health Minister undertook that the Ministry would obtain information from other European countries as to whether they have introduced protective measures against 'Odour and Chemical-Hypersensitivity' (Multiple Chemical Sensitivity or MCS).

The Ministry has, via the Ministry of Foreign Affairs [Ministeriet Udenrigsministeriet], asked 11 countries, to which Denmark normally compares itself, for responses to the following three questions:

Q1) Is MCS Recognised as a disease?

Background to the question:

The 'MCS Association of Denmark' [MCS-Foreningen i Danmark] claims that MCS is a recognized disease in Germany, Austria and Luxembourg under various World Health Organisation (WHO) disease classification codes. The Ministry of Health has no knowledge as to whether this information is correct. The Danish Health Board [Den Danske Sundhedsstyrelse] does not recognise MCS as a disease, but describes the phenomenon as a condition ["tilstand"].

Q2) Have any protective measures been introduced into hospitals, schools or other public institutions to ensure that persons who suffer MCS are not exposed to scents or chemicals that could exacerbate their state?

Background to the question:

Special protective measures may include, for example, the use of non-toxic cleaning agents or detergents in hospitals and other public institutions; or for hospital staff to use gentle perfumes which cannot induce symptoms in particularly sensitive patients. There may also be special environmental labelling of products containing toxic chemicals.

Q3) Has there been any introduction of a special "environmental labelling" logo [miljømærkning] for products that contain perfume or toxic chemicals, particularly labels that are directed at people who suffer from MCS?

Background to the question:

In Denmark, all cosmetic products are labelled with declarations of their contents, where you can read what ingredients they contain. Therefore, it is possible for people with allergies to avoid products that contain substances they know they react to. There are no rules about special labelling in relation to persons suffering from MCS. Therefore, it is interesting to know whether other countries have gone further with their labelling rules than Denmark.

Conclusion:

- Q1) Austria replied that they recognise MCS as a disease in the WHO classification as an unspecified allergy. Germany replied that MCS is classified as a "syndrome", "allergy" and "hypersensitivity". No other surveyed countries recognize MCS as a disease.
- **Q2)** Sweden, Finland and Germany have answered question two. The authorities recommend that perfumes and strong detergents be avoided in the public sphere. These spaces may include, for example, institutions for children and hospitals. In some countries it is left to local players to lay down guidelines.
- Q3) On special environmental labelling, Finland, Luxembourg, Netherlands, Sweden, Germany and Austria have replied that they follow the rules in the EU'S directives for cosmetics [EU's kosmetikdirektiv]. Britain follows other EU environmental legislation on labelling. No country has set its own rules in the area.

Each Individual Country's Responses to the Questions:

I) Belgium

- Q1) Belgium does not recognize MCS as a disease, but rather considers it to be a condition.
- Q2) There are no such protective measures as it is considered practically impossible to comprehend the implications they would entail (given the many variants of both the allergic responses and substances concerned). Should we encounter cases of persons with hypersensitivity in the hospital domain or in other public institutions etc., we will then in any case in hospitals take the necessary action for the specific situation.
- Q3) This does not exist in Belgium. Once again, it seems practically impossible to regulate situations in which the degree is variable and diffuse (the same symptoms in different patients do not necessarily share a common scent or chemical triggers, and common scents or chemicals do not necessarily cause similar symptoms in different patients).

II) Finland

- **Q1)** MCS is not classified as a disease in Finland, and there is no specific national legislation or guidance concerning persons who may suffer from this.
- **Q2) and Q3)** Finland applies EU legislation on the classification and labelling of hazardous chemicals, and in Finland there are no special labelling requirements for chemicals or products containing chemicals.
 - Nor is there any official guidance on voluntary labelling to inform hypersensitive persons. Legislation on cosmetics takes sensitive people (such as small children, the elderly, pregnant women and those with a weak

immune system) into consideration when determining the health risks of chemicals and the health risks of exposure to chemicals in cosmetics.

Hospital staff are instructed that they must avoid using strong perfumes. And public spaces shall not be cleaned with strong smelling cleaning agents.

III) France

- Q1) Just as in Denmark, MCS is not recognized as a disease in France. There are, so far as is known by the Ministry of Health, no special associations for people who invoke MCS. But, according to the Ministry of Health, there is increasing attention given to these types of health conditions in France. Therefore they have begun developing a regional network of occupational physicians, district doctors, etc to obtain further information on this type of phenomena. But in the first place they have not chosen to nominate MCS as special strand of study, instead France is particularly focusing on the impact of;
 - 1) electromagnetic radiation
 - 2) dimethylfumarate(DMFU) specially found in furniture, shoes etc. imported from China.

At the same time, they are trying to build up some research units via the district health system [distriktssundhedsvæsenet] to ensure the collection of records of persons who suffer from symptoms that seem similar to allergies, but where no allergy has been demonstrated. This will be part of the basic research work investigating the external environmental effects on public health.

Finally, they are to launch a major scientific study, which will examine the development of the biochemical status of 20,000 children ("biosurveillance"). The increasing focus on allergies has also led to the second French plan for the Environment and Health for 2009-13 to make allergies and their prevention a specific focus. Due to the increasing awareness of the impacts of chemicals in homes, at work places, etc, that may provoke various symptoms, but do not lead to a diagnosis of allergy by medical testing, the Ministry of Health is considering the introduction of a scheme (that is already

operating in, for example, Germany and Luxembourg) involving so-called "Green Ambulances" ["grønne ambulancer"] consisting of experts who can be sent out to places such as private homes where allergic symptoms have been reported but the source has not yet been located. It was also noted by the Ministry of Health that in Canada especially, and also in the United States, there is guite advanced research on MCS and its causes.

Q2) and **Q3)** Since MCS is not recognized as a disease, France has not taken steps to label products to particularly warn those people who suffer from this type of hypersensitivity about the possible consequences on using the products.

IV) Italy

- Q1) In Italy they do not use the [WHO?] classification of recognized diseases. They distinguish instead between two different health conditions, that can give the patients the right to an exemption ("Health Ticket") [("ticket sanitario")] from fees associated with doctors visits and medicines:
 - (1) chronic diseases and
 - (2) rare diseases, which are difficult to medically diagnose.

At the National level MCS is not recognized as a rare disease, and currently the Italian Ministry of Health does not consider it to be necessary to change this status. They do not yet believe that they have the facts that can prove MCS is a disease. However the individual regions are able to recognize MCS as a rare disease, which Tuscany and Emilia Romagna chose to do in 2005. Subsequently, these two regions both removed MCS from the list of "rare diseases". Other regions have chosen to financially support MCS patients treated abroad.

- **Q2)** There are no protective measures in place at the National level, since such actions are regulated by individual regions. Only a few regions have so far confirmed they have started to focus on this problem; discussions are apparently only at a preliminary stage.
- Q3) In Italy there is no particular environmental labelling, directed at people who suffer from MCS, on products containing perfumes or chemicals that is. All

cosmetic products in Italy have declarations of contents, but these do not specify the chemicals that make up the fragrance. At present there is no concrete proposal from either the Italian Health Ministry or the Ministry of Environment regarding the imposition of particular environmental labels, but they are working towards improvement in this area.

V) Luxembourg

- Q1) MCS is not recognised as a disease in Luxembourg. MCS cannot be clearly defined as a condition. This is because of the diffuse nature of its symptoms, which may resemble allergic symptoms. Family Doctors normally recommend patients to undergo extensive allergy testing.
- **Q2)** There are no special protective measures at hospitals, public institutions or other places. It is left to the individual institutions to choose environmentally friendly cleaning products, etc.
- Q3) There is no special labelling for MCS. Luxembourg has implemented the European Cosmetics Directive. The Environment Ministry and "SuperDrecksKescht for Bieger" ("SuperDrecksKescht for Bieger" is an initiative of the Ministry of the Environment and the Chamber of Trades to support companies in establishing and accurate waste management plan) has just launched a new "Clever Alternative" [Clever akafen] logo, to lead consumers to buy organic laundry detergents and cleaning products.

 Products must meet certain criteria (drawn up in cooperation with "The Environment Consultancy" Austria ["die Umweltberatung" Österreich]) for 'FSA' content of surfactants, bleaching agents, solvents and fabric softeners and other additives in order to reduce pollution (and allergies). It warns also against added fragrances, which have absolutely no cleaning value, but are allergenic.

VI) The Netherlands

Q1 – 3)The Health Ministry reported that hypersensitivity is not recognized as a disease, and there are no special measures for public institutions. Specific labelling in relation to MCS has not been implemented.

There seems to be no political attention given to MCS. The independent Scientific Health Council [Gezondheidsraad], which advises the government and the Netherlands Parliament on Health, published a report on MCS in 1999, but has not made any statements since. It may be added that so far as possible, they use the 'register of names' of the International Nomenclature of Cosmetic Ingredients (INCI) to name and label the ingredients of cosmetic products in accordance with EU guidelines.

The Ministry of Health is not aware of the extent to which hospitals, and other health clinics in general, use allergy-friendly detergents. If they do use allergy friendly detergents then it is on each institutions own initiatives.

VII) Spain

- **Q1)** The Ministry of Health has not implemented its own version of disease recognition and pathology codification because they use the WHO's international system of classification of diseases (ICD).
- Q2) Spain has not answered this question.
- Q3) Spain does not carry out specific environmental labelling targeted at those with MCS

VIII) Britain

- Q1) In the year 2000, the British government's "Chemicals in Food, Consumer Products and the Environment Committee" found that MCS is a condition which is largely defined by the patients themselves, and that there is no consistent pattern of symptoms or available data that can define the condition. The range of benefits for the medical examination and treatment of allergies in Great Britain is set locally by the individual trusts of the National Health Service, and thus depends on local needs. There is no regulation of referral of patients to relevant medical specialists for further investigation. Practitioners are expected to exercise their general medical judgement of the patients needs.
- **Q2)** Certain municipal authorities have introduced environmentally friendly procurement protocol for the institutions for which they are responsible.

However, this is not regulated. Furthermore, any such initiatives generally take issues environment into consideration, but not those of human health.

Q3) There is no special labelling for MCS. The control of environmental labelling of consumer goods in Britain is covered by the European Union "Classification, Labelling and Packaging" legislation. Under this legislation sensitisers are listed, but there is no specific category for perfumes or the like.

IX) Sweden

- Q1) MCS is not recognised as a disease in Sweden. For the purposes of the Social Pension [førtidspension] a description of the symptoms that cause a person to be unable to work is needed to determine whether they are eligible for a social pension or an invalid pension. It is not the MCS diagnosis in itself that is decisive but the individual's symptoms and their severity. Denmark therefore notes that in Sweden MCS is only described as a condition.
- **Q2)** According to the available information, Sweden has not implemented specific protection measures in hospitals and other public institutions. However, the Swedish Environmental Protection Agency [Naturvardsverket] (SEPA) prepared a report in 2001 on Swedish environmental objectives, which focus on human health and wellness as one of five basic values. Hypersensitivity, allergies and asthma have increased markedly in Sweden, and according to the Swedish 'Network for Fragrance Hypersensitivity' ['Netværk for Duftoverfølsomhed']around six percent of the Swedish population suffer severe discomfort, to varying degrees. Some of these people find it difficult to use public transportation because they risk encountering a particular fragrance they do not tolerate, and others are no longer able to work without getting sick. Consequently, the SEPA report points out that one of the main tasks in ensuring a sustainable development framework is to reduce the inconvenience for people who already have a hypersensitivity. However, the report did not raise concrete measures as how to achieve this, and concluded that they will be unable to remove these threats to human health before the year 2020.

According to Swedish Work Environment Law [Arbejdsmiljølov] employers have a responsibility to evaluate the safety and health [arbejdsmiljøet] (OHS)

[OSH] of the work environment. The Work Environment Authority [Arbetsmiljöverket] has developed regulations and recommendations for the systematic evaluation of the working environment, which is described in a report of the same name. In this report, factors such as air quality, chemical safety and logistical factors (such as workload and working hours) are identified as having an impact on the employee's work situation, and therefore fall within the responsibility of the employer to take into account. That is to say, managers and employers must be aware of the relationship between the risks involved in working and their OHS implications in relation to disease and accidents. The Social Protection Agency [Socialstyrelsens] has produced a report with general advice on cleaning nurseries, kindergartens, schools and after-school centres. It points out that according the Law on Chemical Products (1985) [lovenom kemiske produkter (1985)], dangerous products should be avoided, and these must be replaced with less hazardous cleaning products. Neither employees nor other people who are in the room should suffer discomfort because of the ingredients in cleaning agents. In particular, children and staff who suffer from allergies or have certain allergic concerns should not be subjected to any exposures that could exacerbate their condition.

"Region Västra Götaland's Fragrance Policy". The mid-Swedish region of Västra Götaland has taken one more step and has introduced a so called "Fragrance Policy" ["Duftpolitik"]. This policy says that you should avoid smoke, perfume, aftershave and other scents which may cause serious discomfort for people with allergies or people who have problems with strong scents. The Fragrance Policy was introduced in 2008, and highlights certain guidelines for personal hygiene products, cosmetics, cleaning agents and smoking habits. It advises training for purchasing officers, to teach them to buy the correct products that comply with the Fragrance Policy. It is also a requirement that health professionals should not smoke (tobacco) while wearing the clothing that they will later wear when in contact with patients. It should be pointed out that the Fragrance Policy can be seen as a guideline, for in spite of prohibition, is does not contain penalties for infringements of the policy. So far, Västra Götaland is the only region in Sweden which has introduced a Fragrance Policy.

- **Q3)** In Sweden there is no particular environmental labelling of products as to the fragrances or chemicals they contain that may specifically affect those suffering from MCS.
 - On 11 February 2010, the Swedish Environment Minister, Andreas Carlgren, suggested amendments to the prudential regulation of chemicals in Chapter 26 of the Environmental Law [tilsynsbestemmelserne for kemikalier i miljølovens kapitel 26]. This could create a more useful and efficient organization of chemical monitoring which mainly involves the following:
 - 1) the municipal responsibility for overseeing the management of chemical products is removed, and local chemical monitoring will instead be regulated at the regulation level [Editors note: this is not clear in the original Danish; I presume this is meant to say "chemical monitoring will instead be regulated through Chapter 26 of the Environmental Law."]
 - 2) All provisions of the Environmental Law supervisory chapter regarding self-monitoring and environmental reporting are subject to the enforcement of EU rules and the Environmental Law framework.

The basis of Sweden's laws and regulations on cosmetics and hygiene products fall under the EU Cosmetics Directive and chemical-classification regulation. The EU chemical-classification-regulation [kemikalie-klassificerings-forordningen] came into force on 20 January 2009, with the primary aim to harmonise the existing rules and labelling criteria with the rules of the Globally Harmonized System of Classification and Labelling of Chemicals (GHS), which was adopted by the United Nations in July 2003. Therefore, further changes proposed for the [Swedish] Environmental Laws and rules on chemical products are made partly because of the new EU Regulation on the classification and labelling of chemicals, but also because certain rules on the use of chemical products are transferred from the EU Cosmetics Directive to the chemical registration regulation. However there is no special labelling for those suffering from MCS.

X) Germany

Q 1) The Federal Ministry of Health and the statutory health insurance funds [lovpligtige sygekasser]have stated that the German health system does not operate with lists of diseases, and there is no administrative or regulatory evidence for the recognition of a disease. There is no catalogue of diseases such as the one used in Denmark (and Sweden). In Germany it is determined on each individual case as to whether the patient has "disease worthy symptoms". The Leading Organisation of Statutory Health Insurance Funds [Spitzenverband Gesetzliche Krankenkassen] has stated that the German disease classification system (Germany's version of the WHO's classification system) classifies MCS as a "syndrome", "allergy" and "hypersensitivity" (classification T-78.4). This diagnosis means that the doctor can issue a sickleave note, and sick-pay may be available. To avoid abuse, most of the German health insurance funds [tyske sygekasser] have a "sick-pay management system" ["sygepenge-management-system"] that allows the fund to verify the patient's diagnosis through the health insurance fund's own medical service. The treatment of MCS patients (including provision of prescriptions) is covered by health insurance funds. To be able to treat an MCS patient for a fee, the doctor just uses the diagnosis classification according to ICD-catalogue (T-78.4).

In the German system the National Association of Statutory Health Insurance Physicians (KBV) [Kassenärztliche vereinigung] pays each doctor a standard amount per patient as a physician fee, this amount is independent of the diagnosis. The KBV then settles subsequent expenditure with the health insurance funds. Therefore, it is true that MCS patients are receiving treatment in Germany, however this is not because MCS is explicitly recognized as a disease, but because there is an exhaustive list of diseases that restrict the ICD-catalogue. The Federal Agency for Labour Protection and Occupational Medicine [Forbundsstyrelsen for arbejdsbeskyttelse og arbejdsmedicin]reports that MCS is not recognized as a occupational disease. The Federal Ministry for Labour and Social Affairs [Forbundsministeriet for Arbejde og Sociale Anliggender] generally recognises occupational allergies to selected chemical substances, for which an employee is entitled to transitional financial support. For example an allergy against flour is recognized as an occupational disease. Annex 1 to the German regulation

regarding occupational diseases lists the diseases recognized as occupational diseases [Bilag 1 til den tyske forordning vedr. arbejdssygdom nævner, hvilke sygdommeder anerkendes som arbejdssygdomme].

- Q2) As for protective measures, the focus in Germany is primarily on the safety of employees and occupational diseases (as mentioned above). The Federal Agency for Labour Protection and Occupational Medicine has informed that there are no specific mandatory precautions to protect people with MCS symptoms. The Federal Agency for the Environment [Forbundsstyrelse for Miljø] generally recommends that people handicapped by MCS should not be excluded socially. Moreover, it is recommended not to use fragrances in public buildings where individuals have no control over the fragrances in the room. With regard to homes, it is recommended that consumers avoid products with fragrances.
- Q3) Germany generally refers to the EU regulations on labelling of sensitizing substances and mixtures (EC Regulation 12-72/2008) that prescribes labels for substances which have sensitizing effects on the skin and respiratory tract.

As for cosmetics, Germany refers to the relevant EU legislation (EC-Regulation for cosmetics 76/768 in the current version). The requirements for the labelling of cosmetic products are specified in sections 4, 5 and 5a in The German Cosmetic Regulation(Link to the Law:

http://bundesrecht.juris.de/kosmetikv/)

Furthermore, the Federal Agency for Environment recommends that manufacturers make available the details of the ingredients in their products so that the consumer can assess whether a product contains a substance to which he/she reacts to.

XI) Austria

Q1) MCS is recognized in Austria as a disease within the meaning of the WHO classification ICD-10 T78.4 (unspecified allergy).

It is not possible purely from an MCS diagnosis to achieve a social pension. If a patient is disabled or has reduced work opportunities because of MCS then

- doctors diagnose patients as having a mental disorder in order for them to have the opportunity to gain a pension.
- **Q 2)** According to the information provided, there are no specific protective measures in public institutions or elsewhere.
- Q 3) Regarding MCS, there is no special labelling of products. Austria has implemented the EU Cosmetics Directive whereby fragrances, etc. must be declared, but there is no general awareness regarding fragrances in products. (Fragrance-Free products are clearly less common in Austria than in Denmark).