

## Possible Health and Social Impacts of Exposure to Mould

The following information was published following a review by the Australian Parliament in 2018 after a serving MP was inundated with similar claims of mould illness after she told constituents that she was unable to continue due to CIRS. While some medical treatment suggestions are made it should be recognised that some treatments and protocols have changed in 2022



### Australian Parliament

## 3. Chronic Inflammatory Response Syndrome (CIRS)

### Overview

#### 3.1

Dr Sandeep Gupta outlined four factors that have been used to define and identify CIRS:

it is a multisystem and multi-symptom illness;

the patient has had 'documented exposure to biotoxins, usually in the form of a water damaged building';

testing indicates the patient has a number of 'abnormal biomarkers'<sup>1</sup>; and

the illness responds to therapy, 'the main one being cholestyramine.'<sup>2</sup>

#### 3.2

MouldLab put forward an estimate that '25 per cent of people are genetically predisposed to biotoxin illnesses, and are more likely to develop the disease and have much stronger symptoms.'<sup>3</sup> Other potential types of predisposition put

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

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forward included 'hypermobility' in the joints, a prior infection of some kind<sup>4</sup>, and/or allergy<sup>5</sup>.

### 3.3

Additional features of CIRS that were described included that it is a chronic condition (lasting more than six months) and that it is 'inflammatory involving multiple elements of immune response'.<sup>6</sup>

### 3.4

Dr Mark Donohoe highlighted that CIRS is considered a syndrome, rather than a disease. Dr Donohoe explained the difference between syndrome and disease and stated:

*A syndrome is an observational gathering of symptoms that are in common between different patients. [For example] in Chronic Fatigue Syndrome we have a particular group of people with six months fatigue and five of the eight criteria in addition to it. Do we know cause? No. Do we know treatment? No. There's no one common thing ... You don't have a disease until the consensus of medicine is that you have a disease, and it moves from syndrome to disease at that point, but that's because you have testing or treatment that is widely accepted to work.*<sup>7</sup>

### 3.5

The Department of Health stated that 'some people suffer from a collection of chronic debilitating symptom complexes that have been attributed to exposure to mould', which included symptoms of 'skin sensitivity, chronic sinus inflammation, photophobia, night sweats, light headedness, chronic fatigue, chronic headaches, muscle and joint pains, cognitive impairment, and malaise'.<sup>8</sup>

### 3.6

The Department of Health further stated that there is no evidence to suggest a causal relationship exists between exposure to biotoxins and unexplained complex symptoms.<sup>9</sup> In a separate statement the Department of Health commented:

*... the evidence ... at this stage [is] lacking that there is a causal relationship between exposure to environmental biotoxins and the nature of these essentially unexplained symptom complexes.*<sup>10</sup>

### 3.7

Biological Health Services stated that the term CIRS 'is neither recognised nor has been made legitimate within medicine or the wider academic community'.<sup>11</sup>

### 3.8

The Royal Australasian College of Physicians (RACP) agreed and stated:

*... sufficient research has not been conducted nor consensus reached for the terms 'biotoxin-related illnesses' or 'Chronic Inflammatory Response Syndrome (CIRS)' to be used as valid diagnostic labels.*<sup>12</sup>

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

### 3.9

The RACP further stated that 'inappropriate labels can mislead efforts to improve the health and wellbeing of people with symptoms.' As such, the RACP preferred to refer to these patients as people with 'multiple not-readily-explained symptoms'.<sup>13</sup>

## Identification and Treatment of CIRS

### *Reaching a diagnosis*

#### 3.10

The Department of Health outlined the steps a person could take if they are concerned about health impacts that may be associated with mould exposure. This involves first consulting a general practitioner (GP), who may refer a patient to a clinical immunologist or allergist if necessary.<sup>14</sup>

#### 3.11

The Department of Health stated that these specialists 'have available specific diagnostic approaches including bedside allergen testing as well as referral to pathologists for in-vitro laboratory-based testing.'<sup>15</sup> The Department of Health further advised that respiratory physicians may also be consulted to investigate hypersensitivity illness or other respiratory illnesses.<sup>16</sup>

#### 3.12

In relation to people who describe having a multitude of chronic symptoms, the Department of Health stated that it noted:

*... the importance of a multidisciplinary approach to patient care, involving general practitioners as well as specialists such as general physicians, infectious diseases physicians, clinical allergists, clinical immunologists and psychiatrists. A number of potential causes of these debilitating symptoms may be relevant and, as a result, each patient should undergo a thorough clinical assessment that considers the patient's complete history as well as appropriate referral for diagnostic investigations.*<sup>17</sup>

#### 3.13

The Department of Health further explained that a comprehensive assessment is necessary to ensure any undiagnosed illnesses and underlying conditions are identified and treated.<sup>18</sup>

#### 3.14

The Department of Health stated that:

*... the symptom complexes are so similar between people with this condition, the tick-bite associated group and the chronic fatigue group, we're very concerned to make sure that the first thing we do is have everybody properly assessed in a sympathetic and comprehensive way by physicians. In the tick-bite group in Melbourne, we found 40 per cent of them had otherwise undiagnosed illnesses, including brain tumours,*

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

*musculoskeletal rheumatic disorders, and a small number had diagnosable psychiatric illnesses. So our very first priority is to make sure that people don't latch on to a diagnosis because their symptom complexes match what's on a website or a list and that they have a proper comprehensive assessment.* <sup>19</sup>

3.15

Toxic Mould Support Australia (TMSA) stated that 'there are relatively few general practitioners in Australia who are aware of CIRS and who can diagnose and treat the condition.'<sup>20</sup> The Australian Chronic Infectious and Inflammatory Disease Society (ACIIDS) agreed and added that there are less than 30 medical practitioners in Australia with any training related to CIRS.<sup>21</sup>

3.16

Dr Gupta similarly stated that one of the 'barriers to being diagnosed and treated for CIRS in Australia' was that:

*There is a vast shortage of general and specialist practitioners who are knowledgeable in the screening, diagnosis and treatment of the condition. Most health practitioners are only aware of common severe mould-related diagnoses, such as allergy or invasive aspergillosis, a severe condition often treated in a hospital setting.* <sup>22</sup>

3.17

To address this, Dr Gupta recommended that CIRS become 'a recognised medical illness' and that 'training for medical practitioners in CIRS needs to be endorsed and funded as a priority.'<sup>23</sup> The TMSA similarly recommended that 'CIRS diagnosis and treatment information be included in the medical curriculum at universities.'<sup>24</sup>

3.18

Further, Dr Gupta recommended that 'specialist practitioners who are knowledgeable about CIRS' be given access to Medicare Benefit Schedule video consultation item numbers in order to treat bedridden and distance patients.<sup>25</sup>

3.19

MouldLab stated that due to the wide variety of symptoms that have been associated with CIRS, 'patients are often misdiagnosed and eventually mistreated, due to the wrong diagnostic.'<sup>26</sup> MouldLab further stated that misdiagnoses include: allergies, fibromyalgia, anxiety and depression, attention deficit disorders, post-traumatic stress disorder, irritable bowel syndrome, Chronic Fatigue Syndrome (CFS), stress and somatisation.<sup>27</sup>

3.20

The RACP advised that 'there is no consensus' related to diagnosing CIRS.<sup>28</sup> The RACP further stated:

*... where we're looking in this setting when we're talking about CIRS is how we're starting to see the gelling together of what should be considered and what shouldn't be*

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

considered. We're in a very embryonic state of defining what it is. There are still out there in the marketplace people who are naive, and [think] it basically doesn't exist full stop.<sup>29</sup>

3.21

The RACP also stated that it would 'express caution' in using the phrase 'diagnostic' when describing a connection between mould and CIRS-attributed symptoms. The RACP stated:

*... [the] phrase 'diagnostic' implies that there is a strong connection that is causative. When we have someone reporting the sense of odour, the sense of moisture or whatever it is that they're reporting—the visual or the olfactory sense being stimulated—it raises the level of suspicion but it's not diagnostic. That's the problem. It's because people assert diagnostic connectivity when the evidence isn't there to actually say that that level of mould in that particular premise is causative. It's an implied association.*<sup>30</sup>

3.22

Dr Donohoe similarly expressed that:

*... you have diagnosis of a disease but you have a contribution to a syndrome. What I'm really saying is there's no diagnostic certainty [in relation to CIRS], because there's no disease certainty yet.*<sup>31</sup>

3.23

Dr Edwards from the RACP stated that he does not use the term CIRS in his clinical practice, as he considers there are 'a multitude of potential triggers', and that 'mould is but one of the potential triggers of the immunological system.'<sup>32</sup>

3.24

The Department of Health explained that establishing causality would involve identifying the specific toxin that may be causing various symptoms. The Department of Health stated:

*In a clinical situation to establish a causality between environmental exposure, you would need to establish what agent is causing it. That is very difficult in this context because the postulated agents that might be in the environment are many ... Without some sort of proof of association between a potentially toxic entity and the symptoms, it's very hard to take this matter significantly further.*<sup>33</sup>

## *Identifying CIRS*

3.25

Dr Gupta stated that he has seen 'many hundreds of patients who appeared to meet the diagnostic criteria for either "provisionally diagnosed" or "confirmed cases" of CIRS.'<sup>34</sup> Dr Gupta described the diagnosis process he uses for CIRS as involving 'history and examination, bedside tests and formal investigations'.<sup>35</sup>

3.26

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

Of these steps, Dr Gupta stated that environmental history is the 'most important part of the assessment' and involves questioning what possible mould exposures a patient may have had.<sup>36</sup> Another aspect for diagnosis raised by Dr Gupta is to determine whether the person is experiencing a 'multisystem illness', affecting more than two body systems.<sup>37</sup>

### 3.27

Further steps that may be taken to identify CIRS include:

Symptoms cluster analysis: MouldLab stated that the described symptoms of CIRS (outlined in Box 3.1) can be separated into 13 different groups or 'clusters', and if a patient presents with symptoms from eight or more clusters, 'this may indicate a positive CIRS diagnosis';<sup>38</sup>

Visual Contrast Sensitivity testing to determine if a patient has an impaired ability to detect visual patterns;<sup>39</sup>

Genetic testing 'to determine if a patient is genetically susceptible to biotoxin illness';<sup>40</sup>

Biomarker testing;<sup>41</sup>

A range of blood tests;<sup>42</sup>

MRI testing using a software program to examine a standard MRI scan for 'any abnormalities in the brain's structure of brain atrophy';<sup>43</sup> and

A deep nasal swab to test for 'Multiple Antibiotic Resistant Coagulate Negative Staphylococci' (MARCoNS).<sup>44</sup>

### 3.28

The ACIIDS commented that some tests that are used for CIRS are not available in Australia and are undertaken in the United States of America. The ACIIDS explained:

*... in Australia medical practitioners are limited in their ability to order the biomarkers specific for CIRS as most of these biomarkers are not available by any [National Association of Testing Authorities] accredited Australian laboratories. Hence diagnostic blood tests need to be forwarded to ... [the] United States.*<sup>45</sup>

### 3.29

Dr Gupta agreed and stated that this presents logistical difficulties for patients, as there is only one lab in Australia (located in Queensland) that 'is willing to forward the blood to America.' In addition, the testing comes at considerable expense and no Medicare rebate is available.<sup>46</sup>

### 3.30

MouldLab recommended the 'establishment of competent biomarker analysis and sampling locally.'<sup>47</sup> Dr Gupta also recommended that Medicare rebates be made available for biomarker testing in Australia.<sup>48</sup>

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

## Box 3.1: Described Symptoms of CIRS

Reported symptoms<sup>49</sup> associated with CIRS include combinations of:

Fatigue

Weakness

Aches

Muscle cramps

Sharp pain

Headache

Light sensitivity

Red eyes

Blurred vision

Tearing

Sinus problems

Cough

Shortness of breath

Joint pain

Morning stiffness

Memory issues

Difficulty with focus/concentration

Word finding difficulties

Decreased assimilation of new knowledge

Confusion

Disorientation

Skin sensitivity

Mood swings

Sweats (especially night sweats)

Temperature regulation or dysregulation problems

Excessive thirst despite frequent water intake

Static shocks

Numbness

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

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Tingling  
Vertigo/Dizziness  
Metallic taste  
Abdominal pain  
Diarrhoea  
Tremors<sup>50</sup>  
Unusual pain<sup>51</sup>  
Migraine/facial pain<sup>52</sup>  
Appetite swings<sup>53</sup>  
Increased urination<sup>54</sup>/nocturia<sup>55</sup>

The Department of Health observed commonalities between many of these symptoms and those associated with CFS and Lyme disease.<sup>56</sup>

The Myalgic Encephalomyelitis (ME)/CFS and Lyme Association of Western Australia (WA) agreed and further stated that some of its members with ME/CFS and/or Lyme reported: mould in their living environment; a mould exposure at the time of becoming ill; and/or recovering after moving out of a mouldy environment.<sup>57</sup>

In addition, the ACIIDS stated that there are a number of conditions that are 'known to commonly intersect with CIRS', or that are 'likely to be worsened by co-existent CIRS.'<sup>58</sup>

## Diagnosis and Treatment of Complex Illnesses

### 3.31

Professor Matthew Cook stated that 'one of the challenges of clinical practice is that many people have symptoms that can't be adequately explained' and that as a result, people 'pursue various avenues to get an explanation.'<sup>59</sup>

### 3.32

The RACP similarly stated that these individuals may explore different options, including 'doctor-shopping', undertaking internet research and/or finding a support network or organisation.<sup>60</sup> The Department of Health added that these individuals are vulnerable to 'exploitation' and 'being sold quackery' in their search for a diagnosis and treatment.<sup>61</sup>

### 3.33

The Department of Health stated that parts of the medical profession have been unsympathetic to people presenting with a range of unexplained symptoms:

*... the medical profession hasn't always been very sympathetic. They've tended to say, 'This disease doesn't exist' and therefore they've downplayed or belittled the symptoms. [The Department of Health is] very strongly of the view that these symptoms are absolutely genuine, serious and debilitating, and need to be taken seriously.*<sup>62</sup>

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

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3.34

The RACP stated that the education system for doctors is 'deficient' in relation to recognising and treating complex, multisystem and/or unexplained illnesses.<sup>63</sup> The RACP stated that this is due to aspects of medical training having a 'compartmentalised' approach to considering body systems, and that it is not until doctors get 'into a general practice setting that we start looking at a more comprehensive overview of multisystem experience again, in terms of what our patients actually suffer.'<sup>64</sup>

3.35

The RACP further stated that, while it is not possible to change the system of educating doctors, 'we can make it more patient centred as we delve into the multidimensional nature of the patient's suffering'.<sup>65</sup>

3.36

Dr Donohoe stated that a barrier to effective treatment of complex illnesses is a 'lack of appropriate funding for prolonged consultations' under Medicare. Further, Dr Donohoe stated a difficulty in treating complex illness was where to 'draw the line with testing'. Dr Donohoe stated that 'diagnostic testing is not cheap, so Medicare is never ... thrilled about something which would escalate diagnostic testing'.<sup>66</sup>

3.37

The ME/CFS and Lyme Association of WA stated that there is a need for 'government-funded specialist chronic illness diagnostic and treatment clinics'.<sup>67</sup>

## *Treatment*

3.38

The *Shoemaker Protocol* was put forward as being a treatment plan for CIRS.<sup>68</sup> MouldLab described the *Shoemaker Protocol* as a 'step-by-step protocol that requires compliance, careful supervision and follow-through'.<sup>69</sup>

3.39

Dr Gupta advised that the *Shoemaker Protocol* involves a number of treatment steps which are 'designed to bring the biomarkers back to normal'.<sup>70</sup> These steps include: people removing themselves from exposure to the biotoxins (which may involve moving house and replacing possessions);<sup>71</sup> giving patients 'binder medications to help remove mycotoxins and other compounds from the system';<sup>72</sup> administering a vasoactive intestinal polypeptide nasal spray;<sup>73</sup> 'correction of inflammatory and hormonal dysregulation'<sup>74</sup> and 'treating of MARCoNS if present'.<sup>75</sup>

3.40

The Department of Health stated that ‘there isn’t established scientific evidence ... that it has been proven to the extent that [the Department] would regard a treatment [for CIRS] as established.’<sup>76</sup>

3.41

Dr Gupta advised that two doctors in Australia have been certified in the *Shoemaker Protocol*, but in 2017 both ‘decided to decertify’, as they found some patients were ‘unable to tolerate the various treatments due to their sensitivities.’ In particular, Dr Gupta advised that cholestyramine, which is used as a ‘binder medication’ in the *Shoemaker Protocol*, was not tolerated by some patients, while natural binders may be tolerated (but are not included in the *Shoemaker Protocol*).<sup>77</sup>

3.42

Dr Gupta outlined the impediments to the diagnosis and treatment of CIRS as including:

‘a vast shortage of general and specialist practitioners who are knowledgeable in the screening, diagnosis and treatment’ of CIRS;

‘the general practitioners trained in this condition are generally limited to the major cities on the east coast of Australia’;

‘the financial costs of undertaking remediation and medical treatment are very high’;

‘the testing is very difficult to access’; and

‘the treatment is arduous, and often patients experience difficulties in tolerating the medical treatments, which requires high levels of experience to manage.’<sup>78</sup>

3.43

In addition, Dr Gupta listed costs associated with developing and recovering from CIRS as including:

‘the cost of remediation of one’s property’, which Dr Gupta stated can be ‘tens of thousands of dollars’;

‘the cost of seeing doctors’, which can involve ‘private fees in addition to the Medicare rebate due to the long and complex nature of consultations’;

‘the cost of medications’, which can include a ‘compounded form of cholestyramine’ at a cost of \$200 per month, other medications which ‘are generally private prescriptions, and are not on the Pharmaceutical Benefits Scheme’, and two nasal sprays which can each cost approximately \$180 per month; and

‘the costs of investigations’ to confirm the presence of CIRS.<sup>79</sup>

### *Clinical Guidelines*

3.44

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

The RACP stated that 'there is a severe lack of any useful guidelines that are consistent and accepted across the different jurisdictions of the populations of Australia'.<sup>80</sup>

3.45

The Australasian Integrative Medicine Association (AIMA) stated that 'the lack of standardised guidelines for the identification, testing and treating of these patients has the potential to compromise patient care and contribute to significant ongoing morbidity'.<sup>81</sup>

3.46

The AIMA also stated that 'currently, many doctors do not feel competent in either recognising or treating environmentally acquired illnesses', and further training for doctors is required.<sup>82</sup> As such, the AIMA called for the establishment of diagnostic and treatment protocols and education in this area for doctors.<sup>83</sup>

3.47

Dr Gupta stated that the development of clinical guidelines would assist GPs to correctly identify the source(s) of symptoms and provide effective treatment. This would also have the effect of ensuring patients 'don't continue to doctor-shop' which can be 'a huge strain on the health system if [people] are just going from doctor to doctor without a correct diagnosis'.<sup>84</sup>

3.48

Professor Cook cautioned that any development of guidelines should include consideration of established medical reactions to exposure to mould, and also avoid medical investigations that are not needed and/or widely accepted. Professor Cook stated:

*... it's very difficult to come up with guidelines in a state of such massive uncertainty, but two things that guidelines can be useful for are to ensure that we don't miss things that we do know about. We do know about asthma, and we do know about some rare fungal induced hypersensitivity syndromes ... We need to be clear that we don't miss those. The second element ... is to avoid unnecessary and unvalidated investigations. We know an enormous amount about the immune system and it's very easy to measure lots of analytes, but, until we have an understanding of a causal mechanism, simply measuring those will not necessarily be a fruitful line of investigation.*<sup>85</sup>

3.49

The RACP explained that 'clinical guidelines will stop excessive over-investigation. They will stop unnecessary investigation in the vast majority of cases'.<sup>86</sup>

3.50

The RACP also recommended the 'adequate resourcing of the processes necessary to get clinical guidelines that are consensus based and accepted across the different vested stakeholder interests'.<sup>87</sup> The RACP put forward the USA Department of

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

Veterans' Affairs guidelines that related to the Gulf War Syndrome as a possible model for guidelines.<sup>88</sup>

3.51

The Department of Health stated that it would:

*... certainly support guidelines for evaluating [and] managing people with these chronic symptom complexes, whether they are believed to be biotoxin associated, tick bite associated, chronic fatigue, electromagnetic—whatever association ... there is enough commonality in them that guidelines [for] that initial evaluation are valuable. We certainly have committed to do that work with the Lyme support group. I've suggested to them that they might want to broaden and interact with the other patient support groups so that we can get some comprehensive guidelines. It may not take us to the specific end point of the disease, but at least we can get the GPs and other health professionals to reset their approach, which is: 'This disease doesn't exist; go away,' rather than: 'You have a serious debilitating set of complex symptoms that we need to properly evaluate and manage and support you.' So definitely we support guidelines in that broader context.*<sup>89</sup>

3.52

The RACP supported the development of a clinical pathway or a 'clinical guideline' for patients that present with 'multiple not-readily explained symptoms'. The pathway or guideline should address the following key issues:

1

*The formulation of clear working diagnostic criteria and an agreed minimum dataset to enable better case-definition, case management and cohort identification for research purposes.*

2

*Development of standardised indices of exposure of damp or mould-contaminated environments on which research and clinical judgement and management can be reliably founded.*

3

*The development of well-designed longitudinal studies to understand the relative contribution of genetics, epigenetics and the range of biopsychosocial factors impacting on those suffering from multiple not-readily explained symptoms.*

4

*Research into the role of various biomarkers which have been championed by some authors in the broader and general literature.*

5

*Research to improve ways of preventing, reducing and removing damp and mould in homes in order to prevent / reduce childhood asthma, especially among children in socio-economically disadvantaged families and communities.*

6

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

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*The development of clinical guidelines based on the evolving evidence derived from the management and treatment of people who suffer from multiple not-readily explainable symptoms; and*

7

*Access to co-ordinated biopsychosocial supports for those people who meet agreed criteria.*<sup>90</sup>

## **Research**

3.53

A range of recommendations for further research were put forward that related to CIRS. Determining the potential prevalence of CIRS among the population and the most effective method for the identification and treatment of CIRS were particular areas of focus.

3.54

The ACIIDS and the TMSA both recommended that research be undertaken to determine the prevalence of CIRS.<sup>91</sup> Dr Donohoe similarly expressed that research was needed to determine the incidence of mould-related illness among the population and whether predictive testing could be used. Dr Donohoe stated:

*... when we look back through complex illnesses, mould exposure is a very commonly reported thing in a well-taken history. And, more importantly, when people leave those environments, they recover. But I can't come to incidence yet, and I'd propose that the research actually is the most important thing to find out how many and who are affected and whether we have predictive testing that we could possibly employ to say not just 10 per cent but this 10 per cent.*<sup>92</sup>

3.55

The AIMA recommended 'clinical research into the nature of biotoxin/mycotoxin illness' be undertaken.<sup>93</sup> In a similar vein, Greencap stated that:

*... the Government needs to develop a platform with the help of industry bodies and stakeholders and provide funding for research into the complex nature of exposure to environmental toxins and inflammation.*<sup>94</sup>

3.56

Further, the ME/CFS and Lyme Association of WA recommended funding for research in relation to:

'the health effects of exposure to mould and biotoxins'; and

'how [this exposure] may trigger or be connected to ME/CFS and Lyme-like symptoms.'<sup>95</sup>

3.57

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

In addition, the ME/CFS and Lyme Association of WA recommended an investigation into testing and diagnosis options for CIRS, including options for them to be made more affordable.<sup>96</sup>

3.58

The Australian Institute of Occupational Hygienists stated that it would 'support a scientific review of non-asthma, non-allergy mould research.'<sup>97</sup>

3.59

Dr Law stated that funding for research into CIRS will be difficult to obtain without CIRS first becoming more widely accepted in the medical profession. Dr Law stated:

*... the medical community has had doubts whether biotoxin illness, or CIRS, [is] a medical entity. There is a gap between a condition occurring, and a condition being recognised. Where there is no recognition, research funding is unattainable, and data will remain scant, if any. We would all like to have answers, but answers need research, and research needs funding.*<sup>98</sup>

3.60

Research into treatment for CIRS was recommended by the TMSA, which stated that 'studies are needed to determine the most efficacious clinical treatments for patients.'<sup>99</sup> Greencap similarly stated that 'the approach to treatment following exposure to [water damaged buildings] requires deeper investigation.'<sup>100</sup>

3.61

Dr Gupta recommended the Australian Government endorse and fund research into the following areas:

'the prevalence of CIRS;

the prevalence of water-damaged buildings in Australia;

the prevalence of susceptible gene types; and

the effectiveness of treatment protocols'.<sup>101</sup>

3.62

The Department of Health was of the view that broader research into the range of unexplained symptom complexes experienced by individuals (such as those associated with CIRS, Lyme Disease, and/or CFS) may be of use. The Department of Health stated that:

*... there might be some value in broadening research to look at the overlap between these groups of patients who do have very similar symptoms, and there may well be some common background in the biology of people so that different triggers might produce the symptoms. That's where I think a targeted call for research in these multiple debilitating symptom complexes that are otherwise not fully explained scientifically in a broader sense might be possible.*<sup>102</sup>

3.63

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

This was emphasised by a large number of witnesses who supported the need for both Australian based medical research and the development of consistent clinical guidelines for medical practitioners.

## **Personal Accounts of CIRS**

### *Introduction*

3.64

The Committee received a large number of submissions from individuals detailing their, or their family member's, experience of living with symptoms associated with CIRS. Most accounts detailed individual experiences of being exposed to mould, often in the home or workplace, which individuals have linked to the onset of symptoms they attributed to CIRS. A wide range of physical and cognitive symptoms were reported, which had significant health, wellbeing and financial impacts.

3.65

Many inquiry participants stated that they had faced difficulties in obtaining a medical diagnosis for their symptoms and finding effective treatment.<sup>103</sup> Of particular concern to a number of individuals was a sense of not being believed by doctors<sup>104</sup>, and that they often consulted numerous GPs and specialists before finding effective treatment.<sup>105</sup> Some inquiry participants pieced-together their own treatment regime,<sup>106</sup> or sought medical advice from interstate or overseas doctors who offered an understanding of mould-related disease.<sup>107</sup>

3.66

Some personal accounts also described being diagnosed with psychological symptoms,<sup>108</sup> referrals to psychologists or psychiatrists, or being prescribed anti-depressants, rather than treatment for physical symptoms.<sup>109</sup>

3.67

An additional concern was the significant financial expense associated with CIRS arising from numerous treatments and tests, relocation costs, and the cost of replacing suspected mould affected property.<sup>110</sup>

### *Mould in the Home and Workplace*

3.68

Inquiry participants, who identified as having CIRS, or CIRS-symptoms, frequently described an incident of exposure to mould.<sup>111</sup> Some inquiry participants also stated that they believed they were genetically susceptible to CIRS.<sup>112</sup>

3.69

Exposure to mould was commonly reported to have occurred at inquiry participants' place of residence (or series of residences)<sup>113</sup> while others described exposure to mould in their workplace.<sup>114</sup> Submissions were received concerning

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

mould affected buildings from across Australia, including Queensland<sup>115</sup>, New South Wales<sup>116</sup>, Victoria<sup>117</sup>, Western Australia<sup>118</sup>, South Australia<sup>119</sup> and Tasmania.<sup>120</sup>

### 3.70

Mould-affected buildings included newly built<sup>121</sup> and older houses<sup>122</sup> and also workplaces.<sup>123</sup> A common feature was that buildings had been affected by water (flooding incident, or ongoing problems) or internal leaks.<sup>124</sup> Concerns raised included:

*'I have lived at my residence ... since circa 2000. I and my family have been experiencing health issues as a result of mould growth (including spores, biotoxins and bacteria). The growth of the mould and bacteria is largely due to a long term water leak ... as a result of a burst pipe in the foundations of the house.'*<sup>125</sup>

*'In 2017, I was exposed to mould in a commercial office space. Mould was found in the air conditioner and in the ceiling tile adjacent [to] the [air conditioning] unit and the mould growth was due to a leak in the roof. I fell ill immediately upon my first exposure.'*<sup>126</sup>

## Health and Wellbeing Impacts

### 3.71

Inquiry participants shared personal accounts of living with CIRS-attributed symptoms, including experiencing multiple symptoms over a long period of time.<sup>127</sup> Ms Monica Clonda described experiencing 'a myriad of symptoms including, but not limited to fatigue, brain fog, headaches, muscle pain and weakness, weight gain and joint pain'.<sup>128</sup>

### 3.72

The most commonly reported symptoms included fatigue<sup>129</sup>; pain and joint pain<sup>130</sup>; memory and concentration problems and disorientation<sup>131</sup>; insomnia<sup>132</sup>; gastrointestinal issues<sup>133</sup>; sinus issues<sup>134</sup>; fever<sup>135</sup>; headaches<sup>136</sup>; and respiratory issues.<sup>137</sup>

### 3.73

Inquiry participants reported impacts on their physical, social and mental health and overall wellbeing. In particular:

*'I have been stripped of who I am/was: almost all of my tastes, preferences, activities, delights, interests etc. can no longer be accommodated.'*<sup>138</sup>

*'I can't do much anymore. I am mostly housebound, but I make sure I go out once each day for an hour or two. Our nanny takes our children on all outings ... I never take our children anywhere by myself anymore.'*<sup>139</sup>

*'I have gone from an extremely fit, healthy individual to a much skinnier, struggling individual ... [I] have so much pain and various problems that are not visible.'*<sup>140</sup>

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

*'Both my daughter and I have experienced profound trauma and distress from this whole experience, which is still ongoing with no clear outcome in sight. The effects and impacts on myself and my young daughter – including on our physical, psychological, emotional, mental health and well-being – have been severe and cumulative ... as a result of a flood event that was not of our making.'*<sup>141</sup>

*'I have had little social interaction since 2012 ... This has resulted in moderate to extreme loneliness ... It is not realistic to expect that patients have family members to fall back on during CIRS recovery ... Numerous friends abandoned their friendships with me because I was not able to initiate contact or organise or participate in gatherings. It tested the levels of compassion and empathy and generosity of the people in my life and sadly the result was that most of them moved on with their lives without me in it.'*<sup>142</sup>

3.74

The intersection of CIRS-attributed symptoms with other complex medical conditions was described in a number of personal accounts.<sup>143</sup> Ms Janice Foster described her experience, and stated:

*I primarily identify as having a condition similar to Lyme disease, but I also have a probable diagnosis of CIRS. I've been debilitatingly ill for the last 17 years and unable to work the last six. Although I have the mould exposure genetic predisposition and MRI results commonly used to diagnose CIRS, some of my other ... results were unexpected, ruling out a definitive diagnosis ... It might seem particularly unlucky that I've ended up with two controversial illnesses, but it's actually quite common.'*<sup>144</sup>

### *Finding Effective Treatment*

3.75

Despite presenting with a range of symptoms, CIRS-affected individuals described having difficulty in gaining a diagnosis and treatment.<sup>145</sup> Some individuals found there was a limited knowledge among GPs and specialists in relation to mould exposure and illness.<sup>146</sup> As a consequence individuals did not always feel they were believed or understood by medical practitioners.<sup>147</sup> Personal accounts of the difficulties that arose while seeking effective treatment included:

*'No practitioner in Australia was able to diagnose or treat me, or offer anything that gave me any relief until I undertook careful avoidance of all mould and found the doctor who treated me for CIRS in 2014. I suffered nine years of steadily deteriorating health and functionality despite consulting over 40 practitioners. Not one of them was aware that mould could have been the precipitating cause, or the factor that was keeping me ill.'*<sup>148</sup>

*The attitude of doctors towards me when I told them I had a mould-related illness was very unhelpful and sceptical. I was ostracised and the lack of consensus, understanding and support was extremely distressing, added to my expenses, exposed me to additional radiation unnecessarily, and prolonged my recovery time as I started to think maybe I had lost the plot ... at a time in my life when I so desperately needed to be understood, nurtured and supported I felt completely alone.'*<sup>149</sup>

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

*'... I began suffering from a range of severe medical symptoms and spent many years seeing doctors, medical specialists (immunology, otolaryngology, toxicology, gastroenterology, psychiatry, etc.), going into hospital ... but never resolving my conditions'.<sup>150</sup>*

*'I have been ignored; belittled, laughed at and dismissed ... [some medical practitioners] are not aware of what this illness does so therefore [assume] I must be mentally ill. The ignorance and arrogance has prolonged my suffering and pain'.<sup>151</sup>*

3.76

Concerns were raised that the medical profession has been reluctant to acknowledge mould-related illness.<sup>152</sup> Further to this, Dr Liz Stringer stated that 'formal recognition will assist patients with CIRS to access the help they so dearly need and for medical practitioners ... to access the resources needed to treat these patients.'<sup>153</sup> There was consensus that it would be beneficial to CIRS patients for doctors to recognise CIRS<sup>154</sup>, or as one inquiry participant suggested 'to see this medical issue being recognised in the "medical world"'.<sup>155</sup>

3.77

Recommendations included initiatives to increase awareness of the need for mould prevention and management<sup>156</sup> and mould-related illness<sup>157</sup> for the medical community, architects, builders and other trades, the public, hotels and accommodation providers, schools and day-care centres.<sup>158</sup> Mrs Nicole A. raised similar concerns and stated that she 'had no idea how dangerous mould could be and people need to be educated and alerted to the dangers'.<sup>159</sup>

## *Financial Impacts*

3.78

The financial impact of living with CIRS was reported to include costs of: medical consultations, testing and health treatments<sup>160</sup> which were often not covered by Medicare<sup>161</sup>, supplements and dietary changes<sup>162</sup>, moving house<sup>163</sup>, and replacing household contents.<sup>164</sup> Having a reduced capacity to work due to CIRS-attributed symptoms was another significant financial cost commonly reported.<sup>165</sup> Some individual concerns were:

*'We have now spent literally thousands of dollars (over \$200 000) including moving house, remediation, buying all new furnishings and belongings, repairs to [our] new house to make suitable for me, medications and medical visits. I have used up much of my superannuation and my partner is paying a mortgage that is over 40 per cent of his pay. I am unable to work as I am so reactive to places.'<sup>166</sup>*

*'The personal financial loss has also been immense, due to direct health costs, such as out of pocket testing, medications, supplements and doctor visits that I estimate as \$75 000 - \$100 000. Other financial costs include loss of income due to inability to work for many years. I can only work part-time at present. I estimate an indirect financial loss of \$750 000 - \$1 000 000 over the 18 years.'<sup>167</sup>*

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

*'I earned a six-figure salary, and now I have been living off an income that doesn't even cover basic living costs, and I'm not even including rent in this. I'm unable to seek proper specialist medical treatment, because I can't financially. It is crippling. For example, one medication I take is \$700 for a bottle. A bottle lasts five days.'*<sup>168</sup>

*'... I haven't been able to work. Once WorkCover payments ceased at the end of last year, our household lost a total income. That's difficult because we've been a two-income family ... It's difficult to go back to being a one-income family. Of course, there are the medical expenses on top of that, so it's reduced income and extra medical expenses.'*<sup>169</sup>

## **Managing Mould in Buildings**

3.79

Strengthening regulations and obligations of real estate agents and landlords to remediate and manage mould was put forward as a way to reduce indoor mould exposure for tenants.<sup>170</sup> This was also supported by an inquiry participant who suggested the development of 'guidelines or regulations ... particularly for commercial and rental properties to ensure air quality does not impact human health'.<sup>171</sup> Another concern raised was that mould-related issues are not always identified in building inspection reports, which may limit the ability of prospective occupants to make informed decisions.<sup>172</sup>

3.80

Gutter installation methods that leave a gap for overflow during significant rain events was identified as a way of avoiding water damage to buildings.<sup>173</sup> One inquiry participant reported being advised by their local council that compliance regarding this issue is a 'grey area'.<sup>174</sup> Similar concerns that were raised included:

*'... compliant installation provides a 10 millimetre gap between the back of the gutter and the front of the fascia ... Our gutters have been installed flush against the fascia, leaving no overflow gap. Overtopping storm water will flood over the eaves lining and into the house.'*<sup>175</sup>

*'... I know there are a few building companies of integrity who use the 10 millimetre gap method, but most ... don't comply with gutter installation requirements and are not brought to notice.'*<sup>176</sup>

3.81

Inadequate building ventilation resulting in moisture build up was also recognised as a contributor to mould problems.<sup>177</sup>

3.82

Adding to the financial burden of mould-affected properties, insurance did not always cover the cost of mould-related damage to property and/or belongings.<sup>178</sup> One inquiry participant outlined their experience and stated:

*'... I disposed of over two-thirds of my belongings as they were contaminated by the biotoxins from the water damaged house and could not be guaranteed to be treated and*

**Tel: 0800 0843 083**

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**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

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*free from biotoxins in the future ... as the leak in the shower did not meet my contents insurance policy terms of reference I was not able to claim any insurance on my damaged belongings'.<sup>179</sup>*

3.83

Current and former tenants had been affected by mould in residential<sup>180</sup> and commercial rental properties.<sup>181</sup> Some recounted protracted dealings with real estate agents and landlords who did not respond satisfactorily or comprehensively to mould in dwellings. One inquiry participant stated:

*'There were many leaks over the years that were either dealt with very leisurely, carelessly or never, despite being reported to the estate agent or landlord ... We often had to wash mould off the walls and ceiling of the lounge, dining room, kitchen, little back room, bathroom and all the internal doors.'<sup>182</sup>*

3.84

In addition, a number of individuals with CIRS reported difficulty in finding a mould-free home.<sup>183</sup> Personal experiences included:

*'The first step of my treatment program was to find a mould free home to live in. With the prevalence of [water damaged buildings] being approximately 40 per cent of new build homes along with the issue of not being able to detect hidden mould in wall cavities, in roof spaces and under floor boards. This was by far the hardest challenge.'<sup>184</sup>*

*'... it took over 12 weeks to find an appropriate property to recover in ... I looked at over 30 rentals many of which appeared to be affected by water damage'.<sup>185</sup>*

## **Concluding Comment**

3.85

The illness that has been termed by some as *Chronic Inflammatory Response Syndrome* (CIRS) has been associated with a range of physical and cognitive symptoms, which can affect multiple systems within the body. Commonly reported symptoms by individuals experiencing CIRS included: fatigue, pain, memory and concentration difficulties, disorientation, insomnia, gastrointestinal issues, sinus issues, fever, headaches and respiratory issues.

3.86

The Committee received evidence from individuals who say their exposure to biotoxins is associated with the onset of CIRS. Further, it was put forward that a common cause of biotoxin exposure is through working or living in a building with significant mould growth or water damage.

3.87

CIRS has been defined as a syndrome, which is different from a disease. In particular, the Committee heard that a syndrome may not be supported by a

consensus medical view regarding cause, testing and/or treatment and that there are no clinical guidelines pertaining to CIRS or CIRS-like symptoms.

3.88

A range of tests were put forward as being used in combination to determine whether a patient was experiencing CIRS. These included blood and biomarker testing, MRI testing, genetic testing and testing of visual abilities. Treatment that has been used for CIRS also involves a number of steps which can include remediation of a dwelling and/or belongings, and a range of medications. The Committee received evidence that elements of this diagnosis and treatment regime are costly, not widely available in Australia, and may be lengthy.

3.89

Many inquiry participants who provided personal accounts of living with CIRS-attributed symptoms stated that they had experienced difficulty in identifying CIRS and then finding effective treatment, and that they had often visited multiple doctors in the interim.

3.90

Individuals who provided the Committee with personal accounts of experiencing CIRS also described difficulty in finding a dwelling or workplace that was mould free and did not impact on their health.

3.91

Throughout this inquiry, the Committee was presented with a range of views regarding CIRS. The Committee heard from the Department of Health and some medical practitioners that CIRS is not widely recognised in the medical profession, and that there is insufficient medical evidence regarding the identification of a common cause of the symptoms that have been associated with CIRS.

3.92

The Committee also heard from other medical practitioners in Australia who have identified and treated CIRS in many patients. In addition, the Committee received personal accounts from individuals who identified as having CIRS or having experienced symptoms associated with CIRS. These individuals outlined the significant financial, health, and social impacts of living with a multi-symptom illness, often for many years.

3.93

The Committee was concerned to hear that often desperate individuals experiencing ongoing debilitating symptoms are turned away from mainstream medical practitioners and may be exploited in 'being sold quackery.'

3.94

Complex illnesses such as CIRS and other biotoxin-related illnesses can be difficult to diagnose and treat. Consideration of options to improve the diagnosis and

**Tel: 0800 0843 083**

**Mob: 07990 500 999**

**W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)**

**E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)**

**Company Registration Number: 8837566**

treatment of complex illness and unexplained symptoms may help to reduce the social and financial burden for individuals, ensure doctors are provided with adequate support and training, and reduce the resulting impact on the health system.

## **Recommendation 5**

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3.95

The Committee recommends the Department of Health conduct a review into the treatment of patients presenting with complex illnesses that are difficult to diagnose such as those with CIRS-like symptoms. This review should consider:

methods to ensure patients with complex conditions, such as individuals reporting to have CIRS, are provided with effective and timely treatment and support (with the aim of reducing 'doctor shopping'); and

whether doctors require further support in order to: identify environmental impacts on health; manage complex conditions; and provide appropriate treatment.

## **Recommendation 6**

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3.96

The Committee recommends that the Australian Government commission the National Health and Medical Research Council to conduct research into CIRS-like syndromes with a view to assisting in the diagnosis, treatment and management of patients. Research should also examine any links between mould and biotoxins and complex symptoms most commonly reported as typifying CIRS.

## **Recommendation 7**

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3.97

The Committee recommends that the Department of Health, in consultation with patient groups, medical practitioners, and health bodies, develop clinical guidelines for general practitioners for the diagnosis, treatment and management of CIRS-like conditions.

Mr Trent Zimmerman MP

Chair

8 October 2018

Tel: 0800 0843 083

Mob: 07990 500 999

W: [www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)

E: [jeff@buildingforensics.co.uk](mailto:jeff@buildingforensics.co.uk)

Company Registration Number: 8837566