All-Party Parliamentary **Carbonmonoxide** Group In partnership with



All-Party Parliamentary Carbon Monoxide Group

The Brain and Carbon Monoxide: The impacts of carbon monoxide poisoning on mental health and wellbeing

About the All-Party Parliamentary Carbon Monoxide Group (APPCOG)

The All-Party Parliamentary Carbon Monoxide Group (APPCOG) is the leading forum for Parliamentarians from both Houses and all parties to work together discuss ways of tackling carbon monoxide (CO) poisoning, improve government policy on CO safety, and raise public awareness of the threat posed by deadly CO gas.

Through its busy programme of events and research, the APPCOG seeks to push the vital issue of CO safety up the political agenda. In doing so, the APPCOG works closely with a coalition of CO campaigners, charities and energy industry companies committed to tackling CO poisoning in the APPCOG Stakeholder Forum. The Group also connects Parliamentarians with specialist advice from its working groups, which are made up of medical, healthcare, science and research, and communications professionals. Recent reports by the APPCOG include 'Carbon monoxide alarms: keeping tenants safe and secure in their homes' and 'Carbon monoxide poisoning: saving lives, advancing treatment'.

Background

CO is a poisonous gas given off when a carbon-containing fuel burns incompletely. Once inhaled it binds to haemoglobin forming carboxyhaemoglobin (COHb) and deprives vital organs and tissues of oxygen, as well as being directly toxic to cells. Each year CO poisoning causes over 30 deaths and 200 hospitalisations, as well as approximately 4,000 visits to A&E in England and Wales.¹ CO exposure lasting less than 24 hours is known as acute; poisoning lasting more 24 hours (usually at a lower level) is known as chronic exposure.²

CO exposure causes a variety of non-specific symptoms, including: headaches; nausea; vomiting; lethargy; flulike symptoms; dizziness; confusion; shortness of breath; abnormally rapid heart rate; fainting; seizures; and paralysis.³ These symptoms become more severe as exposure levels increase, with high-level exposure capable of causing coma and death within minutes.⁴

There are also a number of neurobehavioural and neuropsychological symptoms associated with CO poisoning, including changes in memory, cognition and mood.⁵ Prolonged exposure to non-lethal levels of CO can cause lost-lasting effects on the brain including 'epilepsy, emotional instability, accumulation of fluid within the brain (cerebral oedema), and Parkinsonism.'⁶ Symptoms can appear days, weeks, or months after initial exposure and last many years.⁷

⁵ Ibid., p. 36.

¹ Policy Connect. (2017). Carbon monoxide poisoning: saving lives, advancing treatment. [Online]. Available at: https://www.policyconnect.org.uk/appcog/research/carbon-monoxidepoisoning-saving-lives-advancing-treatment [Accessed 07 February 2019]., p. 3.

² Ibid., p. 5.

³ Ibid., p. 6.

⁴ Ibid., p. 5.

⁶ Ibid., p. **6**.

⁷ Pepe, G, et al. (2011). Delayed neuropsychological sequelae after carbon monoxide poisoning: predictive risk factors in the Emergency Department, A retrospective study. *Scandinavian Journal of Trauma, Resuscitation and Emergency Medicine*, (19)16, p. 2

The APPCOG has become increasingly concerned over recent years about the lack of understanding of and medical treatment for the impact of CO on the brain. Following our 2017 report, *Carbon monoxide poisoning: saving lives, advancing treatment*, which included a specialist essay on this topic, the APPCOG and its COMed working group set about assembling a range of medical professionals and campaigners with expertise on brain injury, neurobehavioral changes and CO. This document is a write-up of a Parliamentary roundtable held on 30th January 2019. The discussion was chaired by Chris Bryant MP, and focussed on 3 key themes:-

- Improving diagnostic and treatment pathways for CO poisoning;
- The necessity of setting up a specialist clinic for CO victims with long-term neurological & psychological effects; and
- How to reduce the number of CO incidents through preventative measures.

Before the roundtable, participants were sent a background briefing document outlining our current understanding of how CO poisoning, brain injury, and mental health are linked. The APPCOG would like to thank Headway for their help in producing this, and the Gas Safety Trust for sponsoring the roundtable.

Carbon monoxide poisoning as an acquired brain injury

CO damages the brain in different ways: both via oxygen deprivation, and also damage caused by CO's direct toxicity – in layman's terms, 'poisoning the cell'. This damage to brain cells and therefore cerebral structures is classed as an acquired brain injury (ABI). It is believed that some structures, such as the hippocampus, anterior and medial temporal lobe, insula, inferia frontal lobe and cingulate gyrus are particularly susceptible to damage, explaining the observed impact on memory function, mood and behaviour. ⁸ CO victims have reported symptoms ranging from memory loss, depression and personality changes, changes to executive function, anhedonia (the loss of the ability to feel joy or excitement), or even losing the ability to read or write.

As highlighted by our Chair, Chris Bryant MP, whether caused by a concussion or CO exposure, ABI interacts with many different departments of government. Most obviously, it is a health issue – CO poisoning victims are diagnosed and treated by the NHS, with the associated challenges and costs that go with that. CO poisoning also impacts the Department of Work and Pensions. Disabilities caused by CO poisoning, such as the loss of limb function, memory function, or ability to concentrate, can seriously hamper how survivors interact with the job market. This is compounded by the fact that very few assessors for sickness-related benefits have an understanding of ABI and its challenges. Similarly, schools are affected as ABIs caused by CO exposure have a number of long-term consequences for learning such as fatigue and impaired memory, and children with an ABI need extra support in the classroom. Therefore it is crucial that the government takes CO and its impacts on the brain seriously, and supports investment in better diagnosis, treatment, and prevention.

How to address CO's impact on the brain and mental wellbeing

Improving diagnosis

A critical concern expressed during the roundtable was CO patients being let down by a poor diagnostic pathway. What happens to victims of CO poisoning who are misdiagnosed or never reach a healthcare professional? How can we ensure everyone who is affected by CO accesses a prompt and accurate pathway to treatment?

CO poisoning is challenging to diagnose because it produces a variety of non-specific symptoms, such as nausea, headaches, dizziness and low mood, which may be misdiagnosed for more common problems such as flu, food poisoning or depression. Misdiagnosis may result in no or inefficient treatment being given (i.e. a CO victim reporting headaches and low mood being prescribed antidepressants or talking therapies). This is not only a misuse of NHS resources but also risks patients being sent home to the source of poisoning, prolonging exposure. These difficulties are compounded by the variety of entry points patients may use when seeking a diagnosis. Common scenarios include:

Policy Connect | 7-14 Great Dover Street, London, SE1 4YR | policyconnect.org.uk

⁸ Policy Connect. (2017). *Carbon monoxide poisoning: saving lives, advancing treatment*, p. 36

- Presenting at an emergency department (ED) with non-specific symptoms these could range from having experienced a period of unconsciousness to severe nausea, chest pains and dizziness
- Presenting at a GP surgery with non-specific symptoms such as low mood, feeling 'fluey', or a general sense of being unwell
- Being informed by a Gas Safe registered engineer that there has been a CO leak in the home or workplace, and advised to seek medical attention – patients may then choose either an ED or GP.

These scenarios all have different but interlinked challenges. Time pressures on NHS staff make it almost impossible to take full case histories which could point to CO poisoning. Compounding this is a lack of awareness about CO and its long term effects amongst medical professionals, which means that it is often not thought of as a potential cause. Even if CO poisoning is suspected, limits on current diagnostic techniques means it may not be able to be confirmed. COHb has a very short half-life once the patient is away from the CO source and breathing oxygen; if there is a delay in diagnostic tests being administered, a victim's COHb level could be very low or zero. Lack of understanding of this scenario amongst medical professionals often means that CO poisoning is then dismissed, even if all the symptoms point towards it. This is particularly challenging if the patient presents after an engineer has identified a CO leak. The wait-time to get a GP appointment often means COHb won't be detectable, and the initial symptoms may have dissipated. However, the victim is still at risk of long term impact on the brain due to Delayed Neurological Sequelae (DNS). Many GPs are not aware of this and so if a patient was to develop these symptoms later it is often not linked to the initial CO poisoning, leading to inefficient treatments that do not address the root cause.

For experts at the roundtable, the simplest way to ensure correct diagnosis of CO poisoning is to improve the information and training given to healthcare professionals. Good work has been done to improve awareness of CO in EDs, including increasing use of the COMA mnemonic, although there is still more to do. However due to the large knowledge gaps around CO in other disciplines there is an an urgent need for CO awareness work across the medical profession. This is particularly true for GPs and nurse practitioners who have the most contact with potential CO victims. GPs must also have access to reliable tests for CO that can be used in their practices – initially, these could be similar to the COHb blood screening used in EDs.

Whilst increasing access to current diagnostic tests is a short term fix, a priority overall for better diagnosis of CO poisoning must be the development of more reliable tests for the presence of CO. One of the first steps in this is to identify new biomarkers for CO poisoning, which in turn could allow for more accurate diagnostic tests to be developed. This would be particularly useful in identifying poisoning cases where the patient has been away from the source for several hours, chronic low-level poisoning and historic poisoning. Once developed, these improved diagnostic mechanisms should be funded and accessible to EDs, GP surgeries and paramedic crews. Studies into these novel biomarkers therefore require urgent funding.

It is also essential that the above improvements in diagnosis are accompanied by better reporting of CO poisoning diagnoses. Currently, we do not have accurate records of the number of CO diagnoses in GP surgeries across the UK, making it impossible to map the scale of the problem.

These medical efforts should be accompanied by industry initiatives to support diagnostic pathways, with gas engineers ensuring they are giving the correct advice when alerting people to CO exposure in their home, including immediate presentation to a medical professional who can administer the appropriate tests quickly.

FINDINGS:

- 1) NHS bodies and/or the Royal Colleges should improve CO poisoning diagnosis outcomes by investing in training for healthcare professionals to recognise the symptoms and long lasting impacts of CO poisoning.
- 2) GPs should be provided with reliable tests for CO presence to help confirm diagnosis, with a uniform mechanism for then recording and reporting the numbers of CO cases diagnosed.
- 3) Research into novel biomarkers for CO must be properly funded to enable better diagnostic methods to be developed.



Supporting treatment once diagnosed

Unfortunately, even when patients are diagnosed with CO poisoning, they often don't have access to sufficient neurological treatment or support afterwards. This is symptomatic of a systematic failure to properly fund ABI treatment throughout the NHS – a recent report by the APPG for ABI identified a shortfall of 10,000 beds in neurorehabilitation services.⁹ Access to long term support is restricted further if a patient's exposure was milder and produced more subtle neurological and neurobehavioural effects, as they may never be linked to the initial CO exposure by medical professionals.

To address this, the roundtable agreed it is beyond essential to create a specialist outpatient clinic which can provide support to people with long-term neurological and neurobehavioural effects caused by CO exposure, particularly mild to moderate exposure (which is chronically underserved currently). Such clinics already exist for epilepsy and dementia, and have been proven as being both clinically effective and value-for-money. The traumatic brain injury (TBI) clinic at St. Mary's Hospital provides an excellent model for how a specialist CO clinic would operate, as its multi-disciplinary team (MDT) sees patients with a very similar profile of neurological and neurobehavioural symptoms.

In a specialist clinic, patients would first undertake a thorough assessment including functional MRIs, imaging, and neuro-psychological tests, followed by a detailed case history to help identify which symptoms were preexisting and which could be related to CO exposure. This information would determine which neurorehabilitation treatment services – such as speech and language support, occupational therapy and neuro-psychiatry – should be used to address these problems. The complex nature of the brain and of CO itself makes this multi-disciplinary approach essential in caring for the complex and varied challenges survivors of CO poisoning face. Additionally, there is a role for CO nurse specialists to play a role in care in between clinics, as has been done to great effect for epilepsy.

The utility of a specialist clinic stretches well beyond the initial assessment and long-term care for patients exposed to CO. By accumulating data on patients and their symptoms and working with PhD students, the clinic would serve as a vehicle for future studies that can develop innovative treatment methods and refine our understanding of CO's long-term impact on the brain, including via longitudinal studies.

Such a clinic would also be able to monitor and support children exposed to CO in the womb, as CO is particularly damaging to foetuses and can impair development. CO screenings are conducted 8 – 12 weeks into pregnancy, primarily to identify and educate those who are smoking whilst pregnant; however, it has the dual purpose of identifying those who may be being exposed to ambient CO. CO exposure in pregnancy has been linked to foetal and neonatal death, congenital malformations, preterm delivery, low birth weight, and neurobehavioral and neurodevelopmental problems.¹⁰ However, participants were unconvinced about the support for effected families once the children were born, and there is little research into CO's effects on child development. A specialist clinic could therefore monitor and help identify cognitive and neurobehavioral issues in children who were exposed to CO in utero, and provide specialised support as the child develops. Developmental screenings help improve information provided to schools and families on a child's potential cognitive and behavioural challenges, thereby improving that child's long-term outcomes.

FINDING:

4) NHS England, working with research institutions, should develop a specialist clinic for people with long-term neurological effects caused by CO exposure. This will help plug the gap in care provision and enable future studies that will innovate treatment methods. This clinic must cover mild-to-moderate CO cases.

 ⁹ APPG on ABI. (2018). Acquired Brain Injury and Neurorehabilitation: Time for Change. [Online]. Available at: https://www.ukabif.org.uk/wp-content/uploads/2018/10/1533_40pp_APPG-on-ABI_Report_Time-for-Change_2018_AW_SINGLES_WEB.pdf [Accessed 07 February 2019]., p. 14.
¹⁰ Policy Connect. (2017). Carbon monoxide poisoning: saving lives, advancing treatment, p. 32

Preventing CO poisoning

As the Government stated in their November 2018 health and social care policy paper, prevention is better than cure.¹¹ There is much more that can be done to prevent CO poisoning from occurring in the first place through public education about the risks, improving the rate of servicing of appliances, and mandating CO alarms in homes and workplaces.

Firstly, the roundtable agreed that there was an urgent need for more public awareness campaigns about the risks of CO at home and abroad. During leisure activities or foreign travel people are less likely to think about CO poisoning, and may mistake the non-specific symptoms for food poisoning. This is a particular risk when travelling to countries which are less CO-safety conscious. Participants called on the Foreign and Commonwealth Office to advise travellers to take a CO monitor with them when going abroad, alongside a broader public awareness campaign by Public Health England that informs people how to protect themselves from CO poisoning and how to recognise its symptoms.

Another preventative measure supported by participants was addressing issues in sub-standard housing, such as faulty boilers, un-serviced appliances, and a lack of CO alarms. Speaking at the roundtable Shadow Mental Health and Social Care Minister, Barbara Keeley MP, highlighted cases where her constituents had complained about hazardous housing issues that risked their health but their landlords refused to get heating appliances serviced and tenants felt powerless to act for fear of revenge eviction. Chris Bryant MP raised the issue of the price of gas safety checks or new boilers being prohibitive for owner-occupiers who may be asset rich but cash poor. Participants agreed it is essential that homes be suitable and safe for habitation, and called for more to be done in maintaining suitable housing standards that reduce the risk of CO poisoning. This included calling on the Ministry of Housing, Communities and Local Government to make CO alarms mandatory in all tenures.

Finally, the roundtable agreed that CO monitors should be provided free-of-charge as part of the booking in process in first time pregnancies to protect families and their unborn child from CO poisoning. This is especially important because pregnant people, foetuses, and young children are particularly vulnerable to the effects of CO.

FINDINGS:

- 5) Government should seek to reduce CO poisoning by introducing preventative measures, including mandating CO alarms in the home, providing CO monitors in first-time pregnancies, and tackling sub-standard housing that increases the risk of CO exposure.
- 6) Government, namely Public Health England and the Foreign and Commonwealth Office, should do more to raise awareness of CO and inform the public on how to lower the risk of poisoning at home and abroad.

Contact Details

For more information about the work of the APPCOG, Policy Connect or other questions, please contact:

Georgina Bailey

Carbon Monoxide Safety Policy Manager georgina.bailey@policyconnect.org.uk 0207 202 8586

¹¹ Department of Health and Social Care, (2018), Prevention is better than cure: our vision to help you live well for longer, [Online], Available at: https://www.gov.uk/government/publications/prevention-is-better-than-cure-our-vision-to-help-you-live-well-for-longer, [Accessed 07/02/19]