

EU Single Lighting Regulation – LightAware’s proposals for a health exemption for photosensitive people

Thank you for requesting LightAware’s experience of how photosensitivity is diagnosed and treated together with the implications of this in the context of the workability of our proposed exemption to the Single Lighting Regulation. We have set out our response under the following headings:

1. Lighting is an equality and human rights issue.
2. How photosensitivity is diagnosed and treated.
3. How our proposed exemption would work, including validation of the purchaser, restriction of the channels through which bulbs can be sold or advertised, and access to the exemption.
4. Medical research.

1. Lighting is an equality and human rights issue

1a. LightAware’s remit is to raise awareness of the equality and human rights of photosensitive people. The availability of healthy lighting is an equality and human rights issue.

1b. Some people are made ill by fluorescent and LED lighting – these lighting technologies have caused pain, ill health, unemployment and social exclusion to those unable to tolerate them. Photosensitive people have been discriminated against by legislation phasing out well-tolerated incandescent lighting and its consequent replacement with fluorescent and LED lighting. The equality and human rights of photosensitive people will be further eroded if the Single Lighting Regulation becomes law.

1c. Without a health exemption to this regulation, authorities providing public services and employers are prevented from carrying out their duties under EU Equality laws to those who cannot tolerate fluorescent or LED lighting. Without a health exemption, a significant number of people will have NO legal access to electric lighting they can tolerate.

2. How photosensitivity is diagnosed and treated

2a. There are a range of health conditions where photosensitivity is a well-established symptom (see below). However, symptoms caused specifically by modern fluorescent and LED lighting are new phenomena because the technologies causing them are themselves new. In practice, this means the effects have not so far been fully documented and researched and so are not yet completely understood. What is becoming clear is that although some individuals may respond adversely to several different types of lighting, some people who are made ill by fluorescent and LED lighting have no previous condition, including photosensitivity. For example, a person may develop severe headache on exposure to LED lighting, but tolerate bright natural light well. Or individuals may find that measures are effective to control conditions induced by natural light but not new lighting. One case would be the person with a photosensitive skin condition such as lupus

who may react to sunlight and LED street lighting, but while the reaction to sunlight is mitigated by UV shielding products, the same products will not prevent a reaction to LED street lighting.

2b. It is an empirical observation that some individuals become ill during or following exposure to new forms of electric lighting. A request for information about diagnosis and treatment implies that there is already in place test or tests for diagnosis and some treatment that has already been discovered. With any medical condition it can take decades to determine cause(s) and develop effective treatment. Of course, for many conditions no test and no effective treatment has yet been developed. Unfortunately, it seems there is no one single cause or diagnosis of photosensitivity. Our definition (see exemption wording below) has the precise wording it has because of this. We do not entirely understand why some people suffer adverse reactions to fluorescent and LED lights, although the reasons are clear for others such as those suffering from chronic actinic dermatitis (CAD), lupus photosensitivity and xeroderma pigmentosum (XP).

2c. People who are sensitive to fluorescent and LED lighting have individually tried many different potential preventative measures. LightAware has been contacted by people who have used many different varieties of tinted lenses, and migraine and epilepsy prophylaxis and treatment. However, these treatments often do not prevent symptoms. We have also been informed that those with conditions such as epilepsy, migraine, lupus and photosensitive skin conditions may take medications which reduce some of the disability arising from the disease, but which do not "cure" it or reduce the photosensitivity. (Also see example in 2a. above).

2d. In LightAware's experience most sufferers, after trying various treatments, ultimately resort to avoiding exposure to the problematic light source. As the number of inside and outside venues lit by the problematic light source increase, the less venues the person made ill by fluorescent and LED lighting can access without suffering pain and ill health. This leads to social exclusion.

2e. The following groups are made ill or have their condition worsened by fluorescent and LED lighting:

1. People who have a recognised disease or health condition that has photosensitivity as one of its known symptoms. This would include those with lupus, autism, XP, seborrheic eczema, CAD, epilepsy, eye damage, ME, electrosensitivity and migraine.
2. People who previously had no illness recognised as including photosensitivity, but who are nonetheless disabled by fluorescent and/or LED lighting. Standard neurological, dermatological and ophthalmological tests results may sometimes be normal, but nonetheless they are unable to tolerate certain lighting technologies. Symptoms include insomnia, headache, eye pain, skin pain, tongue pain, nausea, confusion, joint pain, dizziness, fainting, or other severe and incapacitating reactions. Some who previously experienced symptoms during and for a limited time after exposure, in time develop disabling chronic conditions after long-term exposure.
3. Because the long-term effects of the newer lighting technologies are entirely unknown, another group must be considered; those who present with no symptoms in the short term but who may develop problems after long-term exposure. This could include the long-term effects of disruption to circadian rhythms, retinal damage and macular degeneration. One problem that has already emerged is the dazzling and painful effect of new LED car headlights to those driving or walking towards them.

4. Those who currently exhibit no symptoms and later develop them or those not yet born who may exhibit such symptoms in future. These people cannot “stockpile” lighting from existing stocks already placed on the market as they do not know they have such a requirement.

2f. It is essential that any exemption to the Single Lighting Regulation covers groups 1 and 2 and that research is undertaken to establish the size of groups 3 and 4. It is important to recognise that in a number of cases photosensitivity cannot be ‘proved’ as such. This is in part because medical ethics prohibits subjecting people to tests that will make them ill, even if they volunteer. (Also see points 3d1 and 3d2 below.) LightAware calls for much more research to be carried out on those who are known to be unable to tolerate fluorescent and LED lighting, and on the lighting technologies themselves, including any long-term effects of the newer lighting technologies. Considering the lack of information on long-term damage that may be caused by fluorescent and LED, it is prudent to allow access to forms of lighting that are less likely to trigger photo-sensitivity symptoms.

3. How the exemption would work

3a. LightAware considers it essential that incandescent light bulbs be made available to cater for the disability and equality needs of photosensitive people as there is no demonstrated alternative available for people with such photosensitive conditions. Our proposed amendment is set out in the table below.

LightAware’s proposed amendment to the single lighting regulation

<p>An alternative proposal for meeting the minimum health and wellbeing aspect of exemption (ii): Annexe 1 section 2 add the following wording –</p> <p>In the wording of the regulation Article 2 Definitions</p>	<p>(h) Light sources provided specifically for use by photosensitive patients (e.g. frosted, pearl or opal incandescent lamps).</p> <p>(18) ‘Photosensitive patients’ People with a specific condition causing photosensitive symptoms and other people who experience adverse reactions to natural and/or certain forms of artificial lighting technology.</p>
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Administering the exemption

3b. This exemption could potentially be administered through the following measures, alone or in combination according to the preferences of individual member states’ healthcare systems and market surveillance authorities.

Validation of the purchaser

3c. Validation of the purchaser could be undertaken through:

- a database of registered users (involving registration number, electronically read card etc)
- user self-certification with occasional spot-checks (as currently required in the UK for VAT exemption when purchasing. For example, dust mite proof bedding for sufferers of asthma or walking aids)
- certification of purchaser by a doctor or other suitably qualified professional (as in a passport photo)
- production of a doctor's note, prescription or medical letter from a neurologist, ophthalmologist, optometrist, dermatologist or other suitably qualified professional.

However, the following points must be taken into account:

- For a functional disability, such as intolerance to substances established as potentially toxic including certain types of lights like LEDs and CFLs, there should legally be no requirement on the part of the person functionally disabled to have any form of 'proof' as regards their disabling condition. Since intolerance is not an illness, with the person concerned perfectly healthy so long as absent from the toxic substance, there is no diagnosis possible of any disease since the condition is not a disease or illness. Instead it is essential that the potentially toxic environment is remedied and made healthy for all.
- To require 'proof' runs contrary to the intention of the UK Equality Act of 2010, disability legislation under the UK Health & Safety at Work Act of 1974 and the UN Convention of the Rights of Persons with Disabilities. 'Proof' is not required in, say, a theatre for a customer to be asked for 'proof' of a disability. Rather, the disabled person is accepted as disabled and provided with the necessary help to cope with their disability in that situation. To require 'proof' is discrimination and is banned, since it is always an individual reaction in particular circumstances.

Restriction of the channels through which bulbs can be sold or advertised

3d. This could be accomplished through relevant light sources being made available through the following channels:

- they could be sold as medical supplies rather than lighting supplies, for example from some pharmacies or disability products suppliers. This would allow the Eco-Design Regulations to allow an exemption for the production of 'medical lighting products' for people with photosensitivity. People accessing the lighting products through pharmacists etc would enable producers to measure the demand for the products.
- being reclassified as medical devices available on prescription across member states under Directive 2011/24/EU. This uses existing procedures, and access to the lighting would be treated as accessing any other prescription product.
- they could be accessed through Government schemes to help disabled people (eg Access to Work in the UK). A Government scheme would be another way of measuring demand for these products.
- they could be prohibited under the regulation from being advertised or sold alongside other lighting products
- they could be labelled as only for photosensitive people.

In addition, all lighting should be labelled with full information regarding flicker rates, spectral content, colour temperature, intensity dispersion capability etc to help photosensitive people and others determine which, if any, of the types of lighting on sale they can tolerate and to select it for future purchases.

Access to the exemption

3e. It is important that any exemption can be accessed BOTH by the individual photosensitive person themselves and their families, and by employers and other agencies and agencies performing public functions on the individual's behalf. It would need to be clear how the exemption is accessed. It would need to be functional in cases such as the following:

- an individual could use the exemption to access safe lighting for their home, and that of an elderly parent they care for

- a workplace could use the exemption to access safe lighting for a photosensitive employee under disability and equality legislation
- a child who is suffering headache from the LED strip lighting at school – the school could use the exemption to apply for alternative light sources in the child’s classroom for the child to receive their education
- a hospital needs to ensure it can provide the full range of services to a photosensitive person, for example a pregnant woman with complex needs. The hospital could use the exemption to apply for well tolerated light sources in a particular area in time for the birth to ensure the mother’s safety
- a place of worship could use the exemption to access safe lighting for a long-standing member who is no longer able to attend due to the refurbishment of lighting in line with the legislation
- a local government body could use the exemption to access sodium street lighting for a photosensitive patient who is unable to tolerate LED street lighting outside their home.

4. Medical research

(i) LEDs, CFLs and blue light:

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dental procedure" *BMJ Case Rep.* (2015) [PMID: 26661286](#). [PMC4680308](#).

(ii) Health harm from blue light at night, LEDs etc.

Brainard GC et al.: "Action spectrum for melatonin regulation in humans: evidence for a novel circadian photoreceptor" *J Neurosci.* (2001) [PMID: 11487664](#).

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European Commission: "[Health effects of artificial light: How does light affect living organisms?](#)" (SCENIHR, 2012)

Garcia-Saenz A et al.: "Evaluating the Association between Artificial Light-at-Night Exposure and Breast and Prostate Cancer Risk in Spain (MCC-Spain Study)" *Environ Health Perspect.* (2018) [PMID: 29687979](#). [Article](#).

Giachello CN et al.: "Magnetic Fields Modulate Blue-Light-Dependent Regulation of Neuronal Firing by Cryptochrome" *J Neurosci.* (2016) [PMID: 27798129](#).

Gooley JJ et al.: "Exposure to room light before bedtime suppresses melatonin onset and shortens melatonin duration in humans" *J Clin Endocrinol Metab.* (2011) [PMID: 21193540](#). [PMC3047226](#).

International Agency for Research on Cancer (IARC), World Health Organization (WHO): "[IARC Monographs Programme finds cancer hazards associated with shiftwork, painting and firefighting](#)" Press Release no. 180 (2007);

International Agency for Research on Cancer (IARC), World Health Organization (WHO): "[Shiftwork](#)" *IARC Monographs on the Evaluation of Carcinogenic Risks to Humans*. 98(2010).

Lunn RM et al.: "Health consequences of electric lighting practices in the modern world: A report on the National Toxicology Program's workshop on shift work at night, artificial light at night, and circadian disruption" *Sci Total Environ.* (2017) [PMID: 28724246](#).

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