

THE ME ASSOCIATION



SENSITIVITIES, INTOLERANCES AND HYPERSENSITIVITIES IN ME/CFS

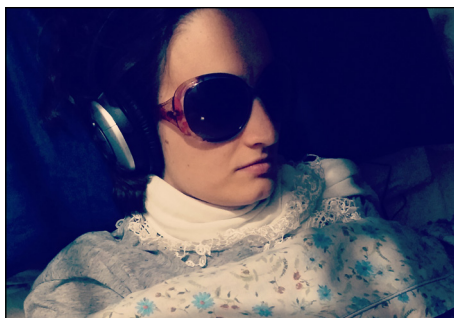
ME CONNECT HELPLINE: **0344 576 5326**

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INTRODUCTION

This leaflet provides information and practical self-help management tips on how to cope with most of the common sensitivities, intolerances, and hypersensitivities that can affect people with ME/CFS.

Many people will develop a sensitivity, or a hypersensitivity to one or more things as part of the onset of ME/CFS or as the illness becomes chronic and/or severe. For some, increased sensitivities to noise, smells, light, touch, etc. are among the most challenging symptoms to manage.



The terms sensitivity and intolerance are to some extent overlapping whereas hypersensitivity implies a far more severe problem.

Common sensitivities experienced by people with ME/CFS - particularly when they are severely or very severely affected - might also involve alcohol, chemicals, smells, drugs, food, pain, and temperature.

Although the cause remains uncertain, and probably differs between sensitivities, one possible explanation is that a viral infection, or whatever immune system stressor triggered

ME/CFS in the first place, resets those control centres and chemical transmitter systems in the brain that are responsible for how we recognise and then react to things like alcohol and chemicals.

In addition, and with some sensitivities, there may be a problem in the way the peripheral nervous system transmits information about pain, touch, noise, light, temperature, etc. from the body back to the brain.

And while there is patient and some research evidence to indicate that various types of allergic disease are more common in people with ME/CFS, possibly as a result of the immune system dysfunction that might be present, the sensitivity problems discussed in this leaflet are not being caused by immune-mediated allergic reactions.

Unfortunately, apart from avoiding or minimising the impact of any known trigger factors, there is no simple solution to any of these problems. And drug treatments are not usually the answer.

Hay Fever

One allergic condition about which we receive fairly regular reports is hay fever - where there is hypersensitivity to plant pollen. This was covered in some detail in a Question and Answer in the Autumn/Winter 2020 (156) edition of ME Essential. We are planning to cover allergies and ME/CFS in a separate information leaflet in due course.

Allergy research reference:

Straus SE et al. Allergy and the chronic fatigue syndrome. The



Sensitivities, Intolerances, and Hypersensitivities in ME/CFS was written by Dr Charles Shepherd (pictured above), Trustee and Hon Medical Adviser to The ME Association.

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Journal of Allergy and Clinical Immunology. 1998, 81 (5 Pt 1): 791-795:

<https://tinyurl.com/45t8vxkd>



A-Z OF SENSITIVITIES, HYPERSENSITIVITIES, AND INTOLERANCES

Alcohol

Alcohol intolerance is a symptom of ME/CFS with many people reporting that it occurred right at the very start of their illness.

As a result, even small amounts of alcohol can produce a hangover-type effect. So most people decide to avoid alcohol completely.

We don't know why this happens. ME/CFS does not affect liver function, where alcohol is metabolised/broken down - so it's unlikely that the problem lies there. A more plausible explanation, which links in with increased sensitivity to drugs that act on the central nervous system, is that there is a similar sensitivity that involves changes to chemical transmitter systems in the brain that are induced by alcohol.

The only published research is a small study that looked at the incidence of alcohol intolerance in ME/CFS (Woolley et al). Two thirds of those interviewed reported decreased use of alcohol - the most common reasons being increased tiredness, hangover feelings, nausea and an exacerbation of sleep disturbance.

We also don't know whether drinking alcohol again after a period of abstinence is going to cause any harm, or delay, to any natural recovery process. Based



on patient evidence it seems that this is a safe thing to do so if this is one of your pleasures in life - providing intake is not in excess, is limited to times when your illness is stable or improving, and that you are not experiencing any adverse effects after drinking alcohol.

Research reference:

Woolley J et al. Alcohol use in chronic fatigue syndrome. *Journal of Psychosomatic Research*. 2004, 56, 203 – 206:

<https://tinyurl.com/5yym3c3w>

Chemicals, smells and multiple chemical sensitivity (MCS)

A wide range of everyday products can cause problems for people who have chemical sensitivities. They can do so via contact on the skin, or through ingestion or smell. Common triggers include:

- pesticides and insecticides
- agricultural chemicals
- moulds and mycotoxins (toxic chemicals produced by moulds/fungi)
- synthetic fragrances – including perfume, fragrances and deodorants
- laundry detergents and fabric softeners
- cigarette smoke and wood-fire smoke
- petrochemical solvents and plastics
- building materials
- preservatives, food colourings, artificial sweeteners, and additives such as tartrazine
- air pollution

- some types of essential oils

Where people have multiple sensitivities a diagnosis of multiple chemical sensitivity (MCS) may be appropriate. MCS on its own can cause a wide range of symptoms - common ones being:

- headaches
- fatigue
- confusion and memory problems
- depression
- shortness of breath
- joint and muscle pains
- skin rashes
- dizziness and gastrointestinal problems

Many of these symptoms overlap with those of ME/CFS, and where appropriate MCS should be ruled out before a diagnosis of ME/CFS is made. However, it is possible for people with ME/CFS to develop MCS which will make future management an additional challenge.

Unfortunately, NHS services for people with MCS can be poor or even non-existent. And although some private doctors and alternative practitioners claim to specialise in MCS, this may involve expensive investigations and treatments - many of which are unproven and need to be viewed with a considerable degree of caution.

Practical tips that may help:

- Try to identify the chemicals and/or smells that are causing you most difficulty
- Minimise contact with them or remove them from your home and, if necessary, advise visitors to not wear any perfumes, etc. that might exacerbate your reaction
- See if you can find alternatives to e.g. cleaning products that are less likely to cause a reaction
- Consider buying an air purifier perhaps for your bedroom or the room in which you spend most time





More information:

You might like to visit MCS-Aware - a UK charity that aims to help people with chemical sensitivities: <https://www.mcs-aware.org/>

Drugs

People with ME/CFS are often more sensitive to drugs and to the side-effects of drugs. This can involve both prescribed and over-the-counter medications, especially those that affect chemical transmitter systems in the brain such as antidepressants and anaesthetics and some types of pain-relieving drugs.

IRRITABLE BOWEL SYNDROME (IBS)

- IBS is a common condition that affects the digestive system
- It causes symptoms like stomach cramps, bloating, diarrhoea, and constipation. These tend to come and go over time, and can last for days, weeks or months at a time
- It's usually a lifelong problem. It can be very frustrating to live with and can have a big impact on your everyday life
- There's no cure, but diet changes and medicines can often help control the symptoms
- The exact cause is unknown - it's been linked to things like food passing through your gut too quickly or too slowly, oversensitive nerves in your gut, stress, gastrointestinal infections and a family history of IBS
- NHS Choices: <https://tinyurl.com/ns32fa34>

Consequently, it is often advisable to start with a low dose of this type of drug, especially antidepressants, and proceed cautiously with gradual increases in dose over a period of weeks. The use of liquid preparations can be useful if a very low dose is required, or swallowing tablets causes difficulties.

Foods

When it comes to food sensitivities and intolerances, the actual causes can be uncertain. Some reactions to food have a clear allergic basis (e.g., a peanut allergy), whereas other reactions can be harder to discern.

Food intolerance and sensitivity can play a role in both irritable bowel syndrome and migraine-type headaches - both of which are more common in people with ME/CFS.

The best way to identify foods that may be causing a problem is normally through the use of an elimination diet where specific foods, or food groups, are excluded from the diet for a period of time to see if this is linked

COELIAC DISEASE

Coeliac disease is caused by an abnormal immune response to gluten, which is a protein found in foods such as bread, pasta, cereals, and biscuits.

It can sometimes be misdiagnosed as ME/CFS because it causes fatigue and irritable bowel-type symptoms. It can be determined by an antibody blood test and should be ruled out before a diagnosis of ME/CFS is made.



LACTOSE INTOLERANCE

Lactose intolerance is a common digestive problem where the body is unable to digest lactose, a type of sugar mainly found in milk and dairy products.

The lactase in your small intestine should break lactose down into sugars called glucose and galactose, which are then absorbed into your bloodstream.

If there's not enough lactase, the unabsorbed lactose moves through your digestive system to your colon (large intestine).

Bacteria in the colon break down the lactose, producing fatty acids and gases like carbon dioxide, hydrogen and methane.

The breakdown of the lactose in the colon, and the resulting acids and gases that are produced, cause the symptoms of lactose intolerance, such as flatulence and bloating.

to any improvement. Undertaking this type of assessment really requires help from a dietitian. You can ask your GP if a dietitian can be recommended or approach a local ME/CFS specialist service.

There are also a wide range of food allergy tests available both privately and on the NHS. However, some of those offered by commercial companies and alternative practitioners are of very questionable value. So do check with your GP before relying on a commercial food allergy test or purchasing expensive allergy treatments.

More information

We have a range of leaflets available to download from the MEA website shop all about diet and nutrition in ME/CFS including a review of dietary trends, malnutrition, the FODMAP diet and



irritable bowel type symptoms. We also have a leaflet covering irritable bowel type symptoms and ME/CFS:

<https://tinyurl.com/4urthurk>

Light

Sensitivity to light, especially bright light from fluorescent or incandescent light bulbs or strong sunlight, is known as photophobia. This can produce uncomfortable or painful feelings in the eye as well as excessive blinking or squinting, watering, and eye strain, and lead to people either avoiding bright light or taking measures to restrict exposure.

Photophobia tends to be more common and pronounced in people with severe and very severe ME/CFS. However, it's important to note that photophobia can also be a sign of an underlying eye condition such as:

- dry eyes
- blepharospasm - where the eyelids flicker uncontrollably
- uveitis - inflammation inside the eye
- keratitis - inflammation of the cornea, the clear layer in front of the eye
- cataracts
- retinal damage

So it's important to have your eyes checked by either your GP or an optician before concluding that photophobia is just another symptom of ME/CFS.

Wearing sunglasses with polarising lenses will help to eliminate glare, especially when outside. Blackout curtains can also help to restrict light coming into a room. However, it's important to note that constant use of light-limiting measures indoors can make photophobia worse by artificially adapting the eyes to conditions that are too dark.

Opticians are a good source of information and guidance on how to manage photophobia. They can help with:



- Reaction lenses in glasses that will adapt to changing light
- An anti-reflective coating to glasses that will help if you have to cope with high intensity indoor lighting in a shop or office
- Tinted glasses
- Yellow tinted glasses - which turn dazzling headlights yellow and may help with night driving

Bright light is also a common trigger factor for migraine-type headaches - which appear to be more common in people with ME/CFS and are often accompanied with an increased sensitivity to smell and noise.

Practical tips and commercial products that may help

- Blackout blinds or curtains
- Blackout eye masks
- Reducing the brightness on a computer screen or loading a programme to recue brightness
- Theraspecs are therapeutic glasses that are designed to filter out harmful blue light which might trigger migraines, etc



Noise

Increased sensitivity to what most people would regard as everyday sounds, and not necessarily loud noise, is called hyperacusis.

Sound not only becomes unpleasant - it can also cause pain. People with hyperacusis are also more likely to hear ringing, buzzing or other strange noises in their ears. This is called tinnitus.

There is no effective drug treatment for hyperacusis. Management is therefore limited to self-help measures such as sound therapy, which can involve wearing an ear piece that makes white noise.

Wearing noise reduction headphones or ear plugs may be helpful but they should only be used when really necessary, e.g., when trying to sleep, as permanent use can make you prone to noise sensitivities at an even lower frequency. One way around this might be to have 'white noise' in the background - e.g. a fan - when sleeping.

More information

The British Tinnitus Association has useful information and guidance on both hyperacusis and tinnitus:

<https://www.tinnitus.org.uk/hyperacusis>

Practical tips and commercial products that may help:

- Flare audio ear plugs. or mouldable ear plugs from a pharmacy
- Noise-cancelling headphones
- Ear defenders - e.g., Peltor
- SensGard hearing protection products
- white noise machines/sounds

Pain

Hypersensitivity to pain, where the body over-reacts to any form of painful event, or minor injury, is called hyperacusis.

It can occur in fibromyalgia, shingles, HIV infection and diabetic neuropathy. It



can also be caused by longer term use of opiate pain-killing drugs.

If the problem is more severe it may be worth asking for a GP referral to a hospital-based pain management service.

The MEA has information leaflets that explain pain and pain management in ME/CFS. These can be downloaded from the website shop.

■ **Coping with Pain in ME/CFS**
e.g., Amitriptyline, Gabapentin, Pregabalin, etc.):

<https://tinyurl.com/49644wu8>

■ **Drugs for Pain in ME/CFS:**

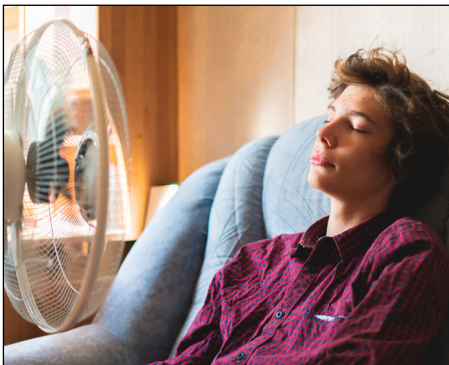
<https://tinyurl.com/v5pesuzf>

■ **MEA information about the NICE Guideline on Chronic Pain & ME/CFS:**

<https://tinyurl.com/4tt2dpbb>

■ Meeus M, et al. Evidence for generalized hyperalgesia in chronic fatigue syndrome: a case control study. *Clinical Rheumatology*. 2010, 29 (4): 393–398:

<https://tinyurl.com/4pt4s3xv>



Temperature regulation – and coping in hot weather

People with ME/CFS almost always have problems with temperature control. This is probably related to a tiny 'thermostat' gland in the brain called the hypothalamus, - which plays a key role in temperature regulation.

In addition, the autonomic nervous system, that controls the size of tiny blood vessels, can become overly sensitive to changes or perceived changes in temperature.

In combination, these problems can make people more sensitive to changes in external temperature, making it harder to cope in hot or humid weather, or with hot baths or showers. They may function better in cooler autumn or winter months.

Conversely, others will find it hard to manage in cold weather and prefer warmer seasons and will need to take additional steps to keep themselves warm.



Practical tips that may help:

To keep you cool when experiencing hot temperatures

■ Wear lightweight and loose-fitting cotton clothes and pyjamas and a wide-brimmed hat if you have to go outside in the heat

■ Drink plenty of fluids to stay hydrated - but avoid too many caffeine-containing drinks

■ Eat small regular meals and switch from hot meals to salads

■ Reduce activity levels in hot weather and stay indoors between 10am and 6pm - unless you really need to go out

■ Be aware of warning signs of heat-related illness/heat stroke - nausea, headache, confusion, muscle cramps, feeling faint

■ Close the curtains and windows during the day in any room where you want to stay cool, especially those that face the sun. Once the heat starts to cool down windows can be opened again in the evening and at night

■ Buy an electric fan for when it's really hot

■ Take a cold 'hot water bottle' to bed at night and keep a cold-water spray handy during the day

■ Have a bowl of cold water and a flannel by the bedside at night to cool down

DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS.



■ Run cold water over wrists and submerge feet in cold water – if you can manage it. A cool shower before sleep can also help

■ Be aware that some drugs (e.g., antidepressants, antihistamines) can also affect temperature-control mechanisms

■ Switch to low-energy light bulbs - as conventional incandescent light bulbs emit more heat - and avoid charging electric equipment in the bedroom overnight

■ Strange as it might seem but a cup of hot tea can actually help to lower body temperature. It does so by stimulating sensory nerves in the mouth which then trigger an increase in sweating. This works best in hot dry weather and when you are wearing loose clothing that allows the skin to breathe.

There are also various types of commercial cooling towels and other cooling products that you might find helpful.

More information:

The MEA's information leaflet discusses the management of temperature dysregulation and cold hands and feet in more detail:

<https://tinyurl.com/r383ywzk>



Touch

Sensitivity to what can be just light touch on the skin from another person, bedding, clothes, and furniture is known as cutaneous or tactile hyperaesthesia. It tends to occur in people with more severe ME/CFS.

This sort of tactile sensitivity can occur in people who have nerve pain/damage in conditions like diabetes as well as in the autistic spectrum disorder - where it may have a developmental origin as touch is one of the first senses to develop after birth. It has also been described in people with COVID-19 infection.

Research reference

Cutaneous hyperesthesia: A novel manifestation of COVID-19:

<https://tinyurl.com/nsmfbepd>

In some cases, sensitivity to touch creates an unpleasant sensation in the skin but it can also cause pain.

Complex regional pain syndrome might also be considered. It is normally confined to one limb and caused by an injury but can spread to other parts of the body and is longer lasting than would normally be expected.

If you have CRPS, your skin in the affected area can become very sensitive. Even the slightest touch, bump or change in temperature can cause intense pain. You may hear this described in the following medical terms:

Hyperalgesia - feeling pain from pressure or temperature that would not normally be painful

Allodynia - experiencing pain from a very light stroke of the affected skin.

NHS Choices has more information about CRPS, causes, and treatments:

<https://tinyurl.com/8y9hyptu>

FEEDBACK AND TIPS FROM THE PATIENT COMMUNITY

We recently asked on social media if people with ME/CFS could explain how sensitivities affect them and if they had any practical ways of coping. This is a selection of the comments we received:

■ Alcohol, chemicals, multi-chemical sensitivity, drugs, light, noise, temperature - all improved (some more than others) over 14 years. But some individual chemical sensitivities worsened, suddenly, due to essential oil exposure, two years ago. Mast Cell stabilisers help slightly.

■ I've started taking Cetrizine Hydrochloride and I've noticed I'm just about tolerating this heatwave without any headaches. Last year, hot days floored me. I'm sleeping a little better and not waking like a zombie.

■ Sorry no advice except to wear sunglasses and to use un-perfumed washing powder. And don't drink alcohol!

■ No alcohol since 2008 diagnosis. Half a glass of wine would wipe me out for days so easy decision in terms of cause/effect. Miss a glass at dinner but it's been so long I'm not sure I'll ever risk it again! Low tolerance to antibiotics and new medications; lots of nausea.

■ Have most of it, except the alcohol intolerance (only experienced that during some months after a bad relapse). All I can do is try to avoid too much of these things. And avoid physical and mental over-exertion,



since that makes me much more sensitive afterwards. I've actually noticed that some alcohol can help my brain to cope with more noise around me at the moment. But of course, that is no good solution since it is harmful in other ways. It is just for special social occasions.

■ Alcohol, chemicals, and drugs. My drug intolerance is/was so bad I couldn't even take vitamins!

■ I have lots of sensitivities. Dealing with some, like alcohol, is easy – just avoid it. For noise sensitivity, I carry noise-cancelling headphones as well as silicone ear plugs. **Temperature sensitivity:** I dress in layers, plan ahead and avoid extremes where possible. **Chemical sensitivities:** be clear with family and outside help about what chemicals can be used in the house. In some ways all of this is probably easier to manage for those of us who are mostly housebound as we spend the vast majority of our time in an environment over which we have some control.

■ Hot temperature is very severe at the moment! Today I have a paddling pool to put my feet in. I keep all the curtains closed when it's sunny and hot. I have fans, I have dog-cooling mats. I have rehydration powders for when it is hot or cold and I can't keep my internal temperature down. I only wear natural fibre cloths, I also have allodynia, so certain fabrics make my skin really uncomfortable anyway!

■ For light sensitivity I have prescription glasses with transition lenses. With heat I use



cotton or natural fibre loose-fitting clothing; layers are always good.

■ All I can do is have a very restricted diet, lie in darkness 24/7, wear ear plugs nonstop. When there are more noises I use noise-cancelling headphones. I use several blankets depending on temperature, and I start new drugs on a very low dose to see if there are side effects.

■ I have high noise sensitivity and I have to praise my noise cancelling headphones. Literally a game changer!

■ Noise sensitivity is my constant. I'm also freezing in temperatures of less than 17 degrees, and light-sensitive during crashes. Summer is better for me, though it seems most actually find the heat worsens their symptoms. I avoid noisy spaces and take frequent breaks from my children (my mum lives with me to provide childcare). I have yet to find an ear plug that I can tolerate. When light is an issue, I am in bed with curtains closed.

■ Temperature, alcohol, orange light mainly, but all light and noise in crashes. I also have multiple skin allergies and sensitivity to certain foods. And I am intolerant to quite a few medications. I can't look at computer screens or my phone for more than a few minutes.

■ I have big issues with alcohol and gluten and have to just avoid both in order to feel okay.

■ For light sensitivity, reaction glasses with an anti-glare coating helps. Turn down screen brightness. Blue (or whatever colour is best for you) backgrounds on documents. Blue-light filter App on phone.

■ Eye masks, black-out curtains, and blinds. Dimmer bulbs in lights and lamps, i.e. low wattage.

■ Sensitive to noise when I'm tired. I turn the volume down on the TV and watch with subtitles when it's too much for me. I'm also sensitive to alcohol, so I only ever have one drink, usually alcohol-free.

■ Sound sensitivity, proper noise cancelling headphones, I can't go out without them. Light sensitivity, 'Sunnies' (that have to wrap

around so the light doesn't flicker through the sides). Touch sensitivity: cutting out tags, cutting hair off (also helps with heat intolerance), 5HTP helps (not for everyone).

■ For being too hot at night, gel pads are great. They come in different sizes. Hot feet? Gel pads under the feet cools them down.

■ I take a daily antihistamine now but the rest is just about manageable without medication. Rest, rest, and more rest.

■ I avoid sulphates and ethanol in alcohol. Also, I can't drink beers and lagers. I totally avoid anything with aspartame and other artificial sweeteners. They can make my symptoms sky-rocket. My ears are very sensitive to noise to the extent that it becomes very painful in loud situations. This then causes me anxiety. The heat is excruciating and when it rises above 21°C I cannot function and I'm so weak. Light can be very difficult to tolerate especially sunlight but also flashing lights.

■ For light I found polarised sunglasses best and have blue-light glasses and use the low blue-light settings on computer devices when I can. Also, I have smart bulbs so I can control the colour and brightness in the house. For noise I love my noise cancelling headphones would love to get some of the newer type that you can choose what you hear through. All my allergies have also increased in this heat, so I've had to increase the dose of most of my asthma and allergy medications.

■ I can't bear being touched as my skin is oversensitive. I also can't tolerate alcohol, aerosols especially those used in furniture polish and at the hairdressers. Mustard - I'm always too hot even when everyone else says it's cold.



Noise in restaurants or radio music. Can't use Ventolin as it makes my asthma worse; I guess it's the aerosol in it.

■ I use noise-cancelling headphones to help in some situations. Mine have a setting that helps mute background noise (good for car journeys). I use some AMAZING ear plugs called Flare that are essential for any group situation or somewhere with multiple stimuli, e.g., shops. They are like hollow ear plugs, and temporarily alter the shape of your ear canal and remove painful frequencies. I highly recommend. Light sensitivity? Constant hats and sunglasses. Anti-blue light glasses in the evening. I have just found out about an eye condition called Irlen syndrome that causes light sensitivity and I'm paying privately to get tested in the hope that they might be able to do something to help.

■ Light, noise, pain, touch and I have to brace myself if there are any changes to medication. And temperature, I have no control over my temperature at all and it can very easily become very overheated or extremely cold.



The ME Association has the largest selection of ME/CFS advice leaflets in the UK on:

Medical Management ■ Mental Health ■ ME Connect ■ Diet & Nutrition ■ General Information ■ Fundraising Leaflets ■ Benefits & Social Care ■ 'To Whom It May Concern' letters

You can download leaflets and buy gifts from our website shop:

<https://meassociation.org.uk/me-association-shop>





ME CONNECT

We're here to help

0344 576 5326



Do you need to talk?

ME Connect is the telephone helpline service of the ME Association. It provides information and support for people with ME and those who live with or care for them.

ME Connect provides a safe and understanding environment for people with ME so that they know they are being heard and understood.

ME Connect is a member of the Helplines Partnership which promotes high standards.

CALL 0344 576 5326
10am-12noon, 2pm-4pm, 7pm-9pm
every day of the year

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