

## Supporting people with Lewy body dementia during the Coronavirus pandemic

The current coronavirus or Covid-19 pandemic is an unsettling and anxious time for everyone. This can be especially so if you have, or care for, someone with a condition such as Lewy Body Dementia which may increase vulnerability to the effects of the virus. Here is some guidance to help support you.

### **Advice for everyone**

Please be aware that this is a rapidly changing situation and it is important to follow the latest news and advice. If you are online, you can check either the official government guidance at <https://www.gov.uk/coronavirus> or NHS information at <https://www.nhs.uk/conditions/coronavirus-covid-19/> If you are not online, the BBC news is a good source of information.

The current advice to halt the spread of the coronavirus states:

- **Wash your hands often** – clean your hands with soap and water for at least 20 seconds. This is especially important after you cough, sneeze or blow your nose, or have been in a public place. If no soap or water is available use hand sanitiser that contains at least 60% alcohol.
- **Practice social distancing** – if you do need to leave the house for any reason observe the 2-metre social distancing advice.
- **Follow the current ‘stay at home’ advice** – only leave the house to shop for necessities and medicine, one form of exercise a day or a medical need. More detailed advice on the current stay at home guidance is available at <https://www.gov.uk/government/publications/coronavirus-outbreak-faqs-what-you-can-and-cant-do/coronavirus-outbreak-faqs-what-you-can-and-cant-do> or <https://www.nhs.uk/conditions/coronavirus-covid-19/>.

## **Advice and information for people with Lewy Body dementia**

People at **increased** risk from the coronavirus include older people, particularly those aged over 70. People with a chronic illness, which includes conditions affecting the brain and nerves, such as Parkinson's disease and Lewy Body Dementia, are also at increased risk.

Further information can be found at <https://www.nhs.uk/conditions/coronavirus-covid-19/advice-for-people-at-high-risk/>

The NHS has also issued a shielded patient list that identifies conditions that place people **most** at risk from the coronavirus. More information, and a full list of conditions included in this extremely vulnerable category can be found at

<https://www.nhs.uk/conditions/coronavirus-covid-19/advice-for-people-at-high-risk/>.

The NHS is currently writing to people who are most at risk. If you have one of these conditions in addition to Lewy body dementia, you may have already received a letter. You can register for additional help if you are classed as a shielded person at

<https://www.gov.uk/coronavirus-extremely-vulnerable>.

People with Lewy Body Dementia are very susceptible to infection and it is very important to reduce their risk of exposure to Covid-19. It may therefore be wise to follow the advice for shielded people in addition to the advice for people at increased risk. This includes remaining at home at all times. Further information is available from

<https://www.nhs.uk/conditions/coronavirus-covid-19/advice-for-people-at-high-risk/>.

In addition, people with Lewy body dementia may experience problems with swallowing, which then increases risk of dehydration and chest infections. This is something that should be closely monitored.

## **Health care**

Where possible seek alternative arrangements for any medical appointments to minimise contact. This could include home visits, telephone or video consultations. Your health care professional will be happy to discuss what alternatives they can offer. If you receive home

visits they will follow all current advice and procedures including washing their hands as soon as possible after entering your home.

If you do need to attend a hospital or clinic, try to minimise risk by avoiding public transport and using a taxi or local patient ambulance services instead. You can feel reassured that risk minimising procedures will be in place at the hospital/clinic. These may include sanitising or distancing measures such as use of in/out only entrances and exits and waiting room spacing.

Many people already have their essential medicine delivered to them by a pharmacy delivery service or in a dosette box. This would be a good time to contact your GP or local pharmacy to arrange this free service.

### **Food shopping**

People with Lewy body dementia should avoid going shopping. If a member of the household is still able to visit a supermarket in person, take advantage of the priority shopping times for vulnerable people. Information about these times is available on supermarket websites or by phoning the store. Remember to observe the social distancing rules in place at the supermarket and to wash your hands as soon as you return home.

Many supermarkets are giving priority delivery slots to vulnerable people. If you have received an NHS shielding letter or registered as most at risk at <https://www.gov.uk/coronavirus-extremely-vulnerable> your information should be available to supermarkets to prioritise you for a delivery slot. Even if you do not fall into the shielded group, supermarkets are still prioritising delivery slots for the elderly, and those at a higher risk. You can contact the supermarket directly to discuss this. Information should be available on individual supermarket websites or by phoning the store.

You may be able to use the 'click and collect' service from your supermarket and ask friends or family to collect the shopping and leave it at your door or ask them to do a shop for you.

Try to eat regular nutritious meals even if you do not feel like it, as this will give you energy and help keep you healthy. Some companies deliver ready meals as an alternative to cooking for example Parsley Box (0800 612 7225) <https://www.parsleybox.com>

### **Daily activities**

People with Lewy body dementia usually respond well to familiarity and the reduction in outside activities and need for new procedures such as frequent handwashing may be unsettling. Try to keep to your normal routine wherever possible while following the current advice to reduce the risk of exposure.

An excellent list of activity ideas for keeping an active mind can be found at <https://www.alzheimers.org.uk/get-support/coronavirus-activity-ideas-people-living-dementia#content-start>. Activities such as simple crosswords or jigsaws, games such as cards or dominoes or looking through photo albums may be good for time spent indoors.

Try to keep as physically active as possible. If it is possible to get into the garden to do some exercise or gardening that will help maintain fitness. If it is not possible to exercise outside this can be substituted with gentle indoor physical activities such as Love to Move (<https://britishgymnasticsfoundation.org/wp-content/bgfdoc/index.php>) or NHS sitting exercises (<https://www.nhs.uk/live-well/exercise/sitting-exercises/>).

### **Sleep**

People with Lewy body dementia cope better when they have had a good night's sleep. Exposure to daylight helps promote better sleep so time spent in the garden should be beneficial. Sitting on a chair at an open door may be an alternative providing social distancing can be maintained.

### **Feeling anxious**

People with Lewy Body Dementia may find it more difficult to understand, keep up with or put into practice public health messages and information. Ways to help include remaining calm and giving frequent reassurance and simple explanations. Watching news updates

which are not fully understood may increase anxiety. It may therefore be advisable to catch up when the person is asleep or in a different room.

Model good practice regarding handwashing and encourage the person with Lewy body dementia to copy. Give gentle prompts or assistance and maybe add a reminder notice above the sink. You could add humour by choosing different songs to fill the 20 seconds. Try not to become too worried or cross if this new routine takes a while to become a habit.

Be aware that anxiety may provoke or exacerbate some of the behavioural aspects of Lewy body dementia such as restlessness. Some advice and tips on dealing with restlessness and calming techniques from Dementia UK can be found at <https://www.dementiauk.org/get-support/coronavirus-covid-19/leaflets-and-information/>

### **Keeping in touch**

The person with Lewy body dementia is likely to miss the friends and family they are used to spending time with. It is important to provide reassurance that this is temporary and that these people still value them and want to stay connected.

- Help maintain contact using video call services such as Skype or WhatsApp
- Phoning loved ones for a chat may be preferable if video calls are unfamiliar and seem confusing. Brief keeping-in-touch calls most days may work better than infrequent long calls.

If the person is in a residential care home, be aware of current restrictions on visiting. Alternative ways to maintain contact could include posting photographs and messages. Some care facilities may be able to set up audio or video calls.

### **If the person with Lewy body dementia becomes unwell**

Be aware of the NHS information and advice on what to do if someone is showing symptoms of the virus, available at <https://www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/>.

Seek medical advice as soon as any symptoms develop, as people with Lewy body dementia are very vulnerable to infections. Make clear to the health care professional that the person has Lewy body dementia. Most GP surgeries are open and the receptionist will arrange for you to be called back if you phone.

People with Lewy Body dementia may be more likely to develop delirium or psychiatric symptoms with Covid-19 infection, and onset or worsening of these symptoms should be a prompt to seek medical advice.

All of the normal health conditions will continue to occur so if the person with Lewy body dementia becomes ill in any way you find difficult to manage at home, for example worsening hallucinations or false beliefs, seek further advice. This could be from your GP or your mental health or dementia services if these form part of your care team. Do not think these services are too busy to contact. If you are concerned, they will want to hear from you.

You could be prepared by packing a hospital bag in advance to avoid a rush if an admission becomes necessary. Remember to include a list of medication and emergency contacts.

It is also a good idea to prepare a document that details your future care wishes and keep this in a safe place so that it can be accessed in case you have difficulties communicating your needs and wants.

### **Advice and information for carers and family members**

Looking after your own physical and mental health is vital to enable you to go on providing care. Dementia UK have produced a guide to help with this, available from their website <https://www.dementiauk.org/get-support/coronavirus-covid-19/leaflets-and-information/>

Stay as physically active as you can by joining in physical activities with the person with Lewy body dementia to encourage and motivate them. You may also find other opportunities if they have a daytime sleep.

Try to get a good night's sleep, even if some household tasks are left unfinished, as you will be better equipped to cope. Music or relaxation guides may help.

If you feel under stress or anxious:

- Try to check the news only once or twice a day, and stick to reliable news sources based in the UK such as the BBC.
- Keep your mind active with engrossing activities when you have time to yourself for example crafts, audio books, puzzle books.
- The NHS Every Mind Matters website has some excellent tips and resources for managing your mental health, this can be found at <https://www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-staying-at-home-tips/>
- Try not to think too far ahead, instead just plan ways to manage the current day.
- Remember that feeling anxious is a very normal reaction to this difficult situation. There are thousands of people working on vaccines and treatments. Your role is to stay safe and manage the things that you can do.
- Stay connected to others for comfort and companionship with video call services such as Skype or WhatsApp or phoning loved ones for a chat. Join online communities or forums if you find these helpful but not if they feel draining or demanding.
- Consider how you have coped with difficult situations in the past and whether those coping methods would help you now. Remember that although the situation is very difficult now, things will eventually improve.
- If you need to provide care for someone from a distance, for whatever reason, an excellent source of advice is available from Dementia UK at <https://www.dementiauk.org/wp-content/uploads/2020/03/Caring-from-a-distance-Coronavirus.pdf>

### **If the Carer or family member becomes unwell**

If you or another member of the household show symptoms of coronavirus, follow the current NHS advice. Make clear that you are a carer in any conversations with health professionals <https://www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/>

Try to think ahead and plan who could support the person with Lewy body dementia if you were unable to for a while. It is a good idea to have this conversation in advance rather than when it is needed.

Similar to the advice above, if a carer or family member becomes unwell due to health issues unrelated to the virus, do not be afraid of making contact with health services.

Be aware that a person with Lewy body dementia may not be able to effectively communicate the symptoms they are feeling – try to be alert for symptoms of the virus.

### **Additional Resources**

In addition to the NHS and government information, additional help and advice can be found via:

- The Lewy Body Society website, available at <https://www.lewybody.org/coronavirus-covid-19/> or by telephone 01942 914000
  - **Helpline 0800 8886678** (Mon-Fri 9 a.m. to 9 p.m./ Sat & Sun 9 a.m. to 5 p.m.)
- The Age UK website, available at <https://www.ageuk.org.uk/information-advice/coronavirus/#>
- The Alzheimer’s Society website, available at <https://www.alzheimers.org.uk/coronavirus>
- The Dementia UK website , available at <https://www.dementiauk.org/get-support/coronavirus-covid-19/>
- The Parkinson’s UK website, available at <https://www.parkinsons.org.uk/news/understanding-coronavirus-and-parkinsons>

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