

INFORMATION SHEET



Coronavirus (COVID-19): People with severe learning disabilities and facemasks

The Government has advised people to consider wearing face masks in places where they are in contact with people outside of their household, and where social distancing may not be possible. As the restrictions around going out are lifted this could include public transport and shops.

Some staff may already be wearing PPE (Personal Protective Equipment). If your relative has to attend a doctor's surgery, dentist or is admitted to hospital the people supporting them will almost certainly be wearing PPE.

Facemasks may become even more necessary if your relative is unable to understand the rules around Social Distancing.

Proactive Preparation:

Wearing a facemask is a relatively new experience in the UK. Your relative may have limited experience of seeing people wearing PPE. They may associate face coverings with unpleasant or painful experiences (eg., a dentist).

Preparing your relative for the experience of wearing or seeing others in PPE is likely to make the experience more tolerable. It may mean that they are able to return to activities and routines they enjoy sooner. Care providers might feel more confident in supporting your relative in the community and to have contact with family if they can wear a PPE.

Remember, wearing a mask doesn't remove the need for social distancing and hand hygiene. It is vital to wash hands before and after using PPE. We have information to help with this here: <https://www.challengingbehaviour.org.uk/learning-disability-assets/handwashinginformationsheet.pdf>

Tolerating others wearing PPE:

For many people with severe learning disabilities, health appointments are already difficult, especially if they are in pain or discomfort. Your relative may struggle to allow unfamiliar people to examine them even before we add PPE into the experience.

Familiar support staff who are now required to wear PPE may be hard to recognise. In particular, some autistic people can find it challenging to recognise someone if their appearance changes. They may react as if being supported by someone unknown to them. The more challenging the situation, the more likely challenging behaviour may be.

What is Desensitisation?:

Desensitisation is a method to teach a person to associate feelings of relaxation with something they previously felt anxious about. Starting from an enjoyable and familiar social situation, the thing the person is scared of can be slowly introduced in a series of easy steps, for example:

- Start by looking at a picture or video of a mask and people wearing masks

- Use the word mask to get your relative used to it
- Show an actual protective mask
- Play with the mask, add it to fun interactions: do this for very short periods
- Next they could be shown different types of mask e.g. scarves/bandanas; funny face masks and a protective mask (or use the funny animal/people masks to make a game of it!)
- Look at videos of preferred people wearing masks in different situations (firemen, superheroes, fancy dress parties, nurses)
- Encourage the person to touch a mask
- The person supporting them could put the mask in front of their own face
- Encourage the person to put the mask up to their staff's face and take it down
- Hold a mask each and encourage your relative to put the mask up to their own face, while you do the same
- It might be useful to use a mirror or photograph so the person can see themselves
- Follow similar steps with the goal of working towards the person being able to tolerate wearing a face covering or mask

Don't rush each step. Over time the person learns not to react with anxiety. You will have to be guided by your relative/the person to ensure that anxiety is kept to a minimum. Rushing the steps may cause greater fear. The key to success is to take small steps and work at a pace your relative is comfortable with. Have fun.

We can learn to cope with difficult things if we are relaxed and supported by people who we know and trust, and if we're not rushed. It often helps to 'embed' a hard activity in a fun or relaxing one.

Suggested activities for desensitisation:

- **Look at pictures of people in PPE**
This could be part of an activity or a game or story about going to the doctors. We have attached a sheet of pictures at the end of this resource that you could use. This resource from Enable Ireland also has some clear images:
[https://www.psychologicalsociety.ie/source/Personal%20Protective%20Equipment%20\(PPS\)%20Social%20Story.pdf](https://www.psychologicalsociety.ie/source/Personal%20Protective%20Equipment%20(PPS)%20Social%20Story.pdf).

Case Study

Sam enjoys looking at books with his family. After looking at a book about doctors, Sam's mum introduces the pictures of doctors wearing their special clothes. She points out their masks and their visors and their gloves and tells Sam that they keep him safe. Sam's mum encourages Sam to look at the book a couple of times a week and so he gets used to seeing people wearing PPE.

- **Handling masks/visors**
Some people with severe learning disabilities like to look at people's glasses and may grab them. To reduce the likelihood of this happening with PPE let your relative play with and explore (clean) masks, aprons and visors if they are available. Let them see you or staff members putting the items on to help them understand that the people underneath the masks are people that they know. It might help for them to have hold of their own masks during appointments.

- **Start to wear PPE for short periods before it is needed**
Wearing PPE for short periods around the person will mean that it can be removed if they become distressed. Over time their tolerance is likely to increase even if only by a tiny amount each day. This means that if PPE has to be worn for prolonged periods by the people supporting them, they may be more likely to tolerate it.
- **Allow touch in controlled environment if appropriate**
If your relative is curious about the PPE whilst it is being worn, they may be less likely to focus on it if they are able to touch it. Consider letting them feel the PPE you or their support staff are wearing if this will not put them or others at risk. This can be limited for a short amount of time, perhaps when the person first arrives.

Other helpful ideas:

- **Allow the person to see family/staff putting on PPE**
This may help the person to recognise the people around them as their familiar staff and therefore reduce anxiety or make new unfamiliar staff easier to tolerate. The PPE guidance for working in home care has a case study on page 13:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/882376/Domiciliary_guidance_England.pdf
- **Wear a photograph of yourself as well as a name badge**
If the person finds it difficult to recognise those around them, they may feel anxious. SCIE suggest 'If you have to wear a mask, consider attaching a laminated photo of yourself to your clothing if that would help the people in your service'. Further information for care staff can be found here: <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff>. It is a good idea to use a photo that the person already associates with you, such as the one on the staff board or in their communication passport.
- **Tell the person who you are**
Letting the person know who you are as you enter the room may help to calm their anxiety and help them to recognise you. Consider repeating this frequently for people who may find it harder to process spoken information.
- **Use an object of reference**
Your relative may find it easier to recognise people if they bring an object that they associate with them along as a visual reminder of who they are. This could be an item of clothing that they often wear or an item associated with their role or an activity that they support your relative to do.

Case study

Danny is a support worker who supports Megan. Usually they enjoy going to the park to play football. At the moment Megan has to stay at home as she has an underlying health condition, but Danny still comes to the family home to give her parents a break. Danny wears PPE when he visits Megan to avoid passing the virus to her. At first Megan does not want to engage with him and is reluctant to go into the garden. When he next visits he brings his football with him when he enters the house to help her to recognise him. Megan is happier to go into the garden with him and enjoys kicking the ball.

Overcoming Sensory Issues:

It is hard to ignore a facemask when you are wearing it. It may make you more able to feel your own breath and it may touch parts of your face as you talk. Your relative may experience sensory difficulties that make them more aware of these sensations or others that you do not notice. There are various types of facemask available and Public Health England have suggested that wearing a scarf or bandana is equally effective. Choose the style that will be most easily tolerated by your relative. They may have a favourite colour or character that can be incorporated into the design. These designs for making your own out of an old t shirt have been published and you could use a favoured fabric or old item of your relative's clothing to make them more likely to accept wearing it:

<https://www.gov.uk/government/publications/how-to-wear-and-make-a-cloth-face-covering/how-to-wear-and-make-a-cloth-face-covering>

Traditional facemasks have elastic that hooks behind the ears and NHS staff have reported that this can be uncomfortable. Below are innovative ways of avoiding the elastic rubbing behind the ears:



Sensory Desensitisation ideas: Again, desensitisation plans can be used to gradually introduce wearing a face covering. It is important to go at your relative's own pace as any kind of pressure may make them reluctant to cooperate.

- **Handle mask**
Let your relative play with and explore (clean) masks, aprons and visors if they are available. You could create games with family/staff that involve putting on and taking off the face mask to build tolerance without any pressure. Remember the idea is to get them to associated feeling relaxed and so make your relative laugh if you can
- **Social stories**
If your relative is familiar with the concept of Social Stories this one from Specs 4 Autism may be helpful: <http://space4autism.com/wp-content/uploads/2020/03/PPE.pdf>

- **Now/Next Boards**

Many people with severe learning disabilities will not be able to understand the concept of a pandemic and that the Government is telling them to wear a mask. A Now/Next Board may help your relative to understand that if they want to do the thing they enjoy they have to wear the mask e.g. Now: mask, Next: shopping, Then: crisps. There are some examples of visual supports including Now/Next Boards here: <https://www.challengingbehaviour.org.uk/learning-disability-assets/nownextlaterchartandvisualtimetable.pdf>.

- **Introduce wearing a facemask when it is not necessary**

Your relative may need some 'trial runs' of wearing a facemask before they keep it on consistently. It might be stressful if your relative takes their facemask off in public, especially when the general public are also feeling anxious at this time. Consider introducing a time to practice wearing the mask when it will not matter if your relative removes it, for example in the garden, before going out. When they can tolerate wearing it for a certain period you could progress to going out. This may not work for everyone because some people may find it difficult to wear a facemask in a place different to the one they have practiced in.

Case study

Emma enjoys going to the supermarket to buy the ingredients for her cooking sessions. Emma's family are worried that members of the public may not tolerate Emma entering the supermarket without a facemask (even though the guidance says she doesn't have to wear one). They decide to follow a desensitisation plan and the last step is wearing the mask for half an hour in the garden. If Emma can wear a mask for half an hour, she will be able to keep it on for the whole time she and her support worker are inside the supermarket. At first Emma only wears the mask for a couple of minutes in the garden before taking it off, her family are positive and don't force her to keep it on. After a couple of weeks Emma will enjoy activities in the garden wearing a mask for half an hour and so Emma's Support Worker feels more confident that she will tolerate it at the supermarket.

Challenging Behaviours

People who display certain behaviours may be more affected by the requirement to cover their nose and mouth than others. They may be thought to present a risk to themselves or those around them. The government guidance states that 'those who may find it difficult to manage them correctly' will not be required to wear a face mask or covering. This may apply to the following situations:

- Pica refers to eating objects which are not suitable to be eaten, such as stones, toys and clothing. Eating inedible material can be very dangerous: people can choke or cause internal harm. A risk assessment should be completed before anyone who displays pica behaviour is introduced to wearing a mask. It is unlikely that the benefits of wearing a mask will outweigh the risks of ingesting material.
- Some people with severe learning disabilities will not be able to tolerate wearing a mask and obliging them to do so may result in challenging behaviour, which can put them or others at risk. Again, a risk assessment should be completed. It may be introducing more outdoor activities that enable social distancing, and that do not

require PPE, may be helpful. For further information please see <https://www.challengingbehaviour.org.uk/understanding-behaviour/finding-the-reasons.html> and <https://www.challengingbehaviour.org.uk/understanding-behaviour/positive-behaviour-support.html>.

The full Government guidance can be viewed here:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/884171/FINAL_6.6637_CO_HMG_C19_Recovery_FINAL_110520_v2_WEB_1_.pdf.

Additional Resources:

This video has been produced by an occupational therapist. Although it refers to children, it may also be helpful if your relative is an adult: <https://bit.ly/youtubefacemaskvid>

Social story about wearing a face mask may help some people to understand why they need to wear a mask: <https://bit.ly/facemasksocialstory>

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Appendix A: Page of pictures of people in PPE: Version 2

