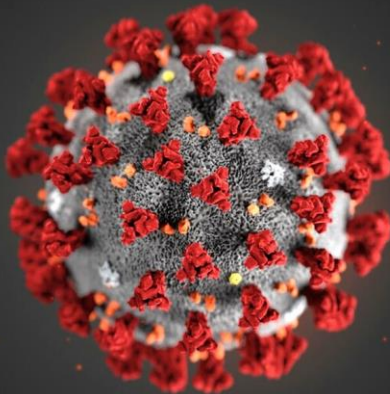




COVID-19

Information booklet



Information and recommendations for the EB Community

Version 1

Introduction

The current novel coronavirus (COVID-19) outbreak has led to a lot of uncertainty and questions, especially from families with children and adults who have a medical condition like EB.

We have collected information from reputable sources and consulted with EB healthcare professionals in the fields of dermatology, infectious diseases, and psychology from different countries to provide you with information on the following:

Impact on EB

What the likelihood of catching the virus is and what the severity of symptoms may be if contracted.

Recommendations

How to prevent catching the virus, your psychosocial wellbeing in self-isolation, and what to do if hospitalisation is required.

General information

What a coronavirus is, where COVID-19 has come from, how it spreads, and the symptoms.

Remember, this is a temporary situation but if you need help, contact your DEBRA group and your EB team/healthcare provider.

Acknowledgments

This booklet was created in collaboration with the following experts:

Dr Anja Diem

Senior Physician at EB House Austria, Austria

Maria Helena Sant Ana Mandelbaum

Dermatology nurse at Universidade do Vale do Paraíba, Brazil

Professor Gunnar Naulaers

Head of the EB team at University Hospitals Leuven, Belgium

Caroline De Reu

EB Nurse at University Hospitals Leuven, Belgium

Sam Geuens

Psychologist at University Hospitals Leuven, Belgium

Dr María Joao Yubero Gonçalves

Paediatric infectious diseases doctor at DEBRA Chile, Chile

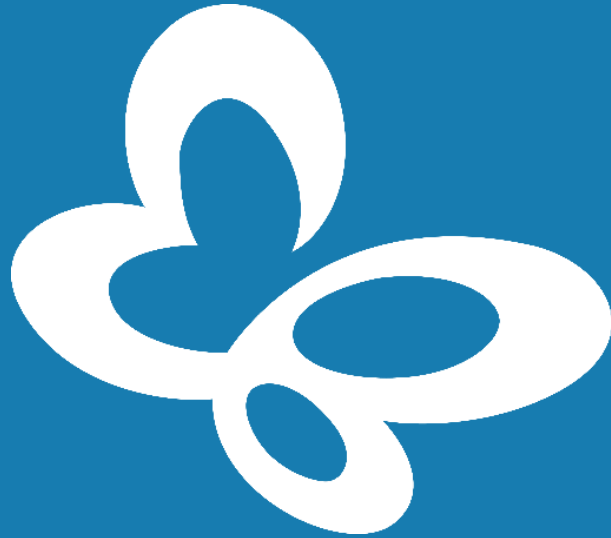
Dr Fiona Browne

Dermatology Consultant at Children's Health Ireland (CHI) at Crumlin, Ireland

Nora García García

Psychologist at DEBRA Spain, Spain

Other sources: [World Health Organization](#)



Impact on EB

I have EB, am I at greater risk of contracting COVID-19?

We would not expect someone with EB to be at any more risk than the general population and as such no additional precautions are required.

Clearly there are some people who will have other conditions that may add risk, others will have hands bandaged and hand washing may not be as diligent as we need so it is important that hands are kept away from the face, and that carers and families practice good hygiene techniques.

If I catch COVID-19, will I have more severe symptoms?

People with localised EB should not be at higher risk than anybody else.

Those with a more severe type of EB can be considered at high risk of having more severe symptoms if they contract the virus. This is because they are already faced with comorbidities, such as anaemia, malnutrition, chronic wound infections, and loss of skin barriers that compromise the immune system.

The best defence is to avoid contracting the virus in the first place

Maintain your normal EB care routine and a healthy diet.



Recommendations

In general, you should follow the recommendations from your national government and health authority. These can change day by day so make sure you keep up to date with them so you have access to the latest information.

The best defence is to avoid contracting the virus in the first place. This can be done through good hygiene and avoiding unnecessary physical contact with other people.

Good hygiene:



Wash your hands regularly and thoroughly with soap and water (for at least 20 seconds) or with an alcohol-based hand rub.



If you cannot wash your hands due to wounds, dressings, or bandages, avoid touching your face as much as possible.



If you cannot wash your hands, change external bandages more frequently if necessary, or use cling film or rubber gloves to protect them.



Caregivers **must** wash their hands thoroughly before and after wound care. Keep as much distance and wear a mask if possible.

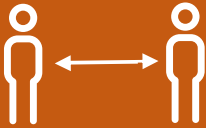


Cough or sneeze into the inside of your elbow or use a tissue. Throw the tissue away immediately after use and then wash your hands.

Avoid unnecessary physical contact:



Stay at home - do not leave unless it is absolutely essential. Work from home if possible.



If you must leave your house, keep a distance of at least 2 metres (6.5 feet) from other people and avoid touching surfaces and objects.



When you return home, disinfect any mobility equipment you have used, such as a wheelchair and leave your shoes outside. If you do unintentionally come into contact with someone (whether they have symptoms or not), change external bandages, remove the clothes you were wearing, wash them, and wash all areas of the body that were exposed if you can.



Keep your house disinfected and avoid consuming food or drinks not prepared at home.



Avoid meeting family or friends who are not members of your household.

Self-isolate if you or a member of your household develop symptoms. If you have EB and need to self-isolate, do this with one caregiver if necessary.



Get the influenza vaccination if it is flu season in your country (consult with your doctor). This vaccine will not protect you against COVID-19 but the chance of contracting the influenza virus will be reduced.

Preparing for hospitalisation:

Make sure you are prepared for hospitalisation. If the recommendations on the previous pages are followed, the odds that this will be the case are very small; however, you should be prepared.



Make sure you have a card with information about EB and with the contact details of your EB team/healthcare provider.



Make sure you have an emergency package with wound care supplies and other items you may need when in hospital.



Talk to your caregivers about how information is transferred in case of an emergency.



Talk to your EB team/healthcare provider if you have any questions.

Minimising psychosocial impact in isolation for adults:



Maintain a daily structure: get up at the same hour, plan activities, have your meals at regular hours, get dressed, and pay attention to personal hygiene.



Acknowledge your feelings. It is perfectly normal to feel worried and anxious in these uncertain times. Try to focus on things you can control not the things you can't.



Share your feelings with people you trust. Reach out to friends and family by calling them or using social media. Reach out for help if you need it. Find professional help if you can't manage alone.



Try to stay calm and focus on normal, daily things. Use techniques that help you deal with stress: humour, meditation, sport, yoga, a distraction, etc.



There is a lot of information coming at you. Try to have access to the correct information and update yourself once a day. Don't check the news every moment of the day.

Minimising psychosocial impact in isolation for children:



Children feel their lives change suddenly so giving them a familiar daily routine can help them cope.



Talk to children about what is going on. There are a lot of booklets and films on the internet to explain COVID-19 to children of all ages.



Support children to continue with normal activities: let them play, go for a walk with them if possible, give them school work, etc.



Try to figure out what they are worried or anxious about to comfort them. Try to keep calm yourself as children will seek comfort from you. Reassure them you will stand through this together and it is not their responsibility to keep themselves safe.



Help them to keep contact with their friends and family.



Restrict their access to the continuing flood of information. Give them a daily update yourself.



General information

What is a coronavirus?

A virus that may cause illness in animals or humans. Many coronaviruses cause respiratory infections ranging from the common cold or flu to more severe diseases like Middle East Respiratory Syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS).

What is COVID-19?

COVID-19 is the infectious disease caused by the most recently discovered coronavirus. This new virus and disease were unknown before the outbreak began in Wuhan, China, in December 2019.

How does COVID-19 spread?

People can catch COVID-19 from others who have the virus.

The disease can spread from person to person through small droplets from the nose or mouth.



People can catch COVID-19 if they breathe in droplets from a person with COVID-19 who coughs out or exhales droplets.



These droplets also land on objects and surfaces around the person. Other people then catch COVID-19 by touching these and then touching their eyes, nose, or mouth.

Disclaimer

The information contained in this booklet does not indicate an exclusive course of action or serve as a standard of medical care. The authors of this booklet have made considerable effort to ensure that the information contained within is accurate and up to date. The authors and DEBRA International accept no responsibility for any inaccuracies, information perceived as misleading, or the success of any recommendations, advice, or suggestions detailed in this booklet.

The information provided within this booklet is subject to change without notice. Updates will be made as and when new information on the COVID-19 pandemic becomes available.