

# Keeping cool in the heat



Summer heat can be extremely challenging for people living with all types of EB. Heat increases the fragility of the skin, new blisters can form because of the heat, loss of body fluid through wound drainage can lead to dehydration and bandages don't allow the skin to sweat and cool. Finding ways to keep cool is critical.

**The NHS website** has information about risks such as heatstroke and dehydration in a heatwave and advice on keeping hydrated and ways to keep cool. Their advice includes drinking plenty of fluids, avoiding the sun during the hottest part of the day, keeping rooms cool by using shades or light coloured curtains and windows closed until it is cooler, having cool baths or showers or splashing yourself with cool water and wearing loose, cool clothing. They also suggest using the free 111 phone and online service for advice if more help is needed.

<https://www.nhs.uk/live-well/seasonal-health/heatwave-how-to-cope-in-hot-weather/>

<https://www.nhs.uk/conditions/heat-exhaustion-heatstroke/>

## Fans and air conditioning

There are a huge range of fans and air conditioning units on the market. Both are constantly being developed and improved, so this is general guidance with a few pointers to help you decide if they are right for you. Please note, if you get used to being very cool a lot of the time, it can affect your ability to cope in the heat.

### Fans

A fan will move around air making the person feel cooler, but it won't cool the room unless it is positioned to bring cooler air from outside into the room e.g. in the evening. The main differences are speed/power, how loud is the fan, how many settings does it have and if it has a timer (helps you set a time to fall asleep and not waste power). Some are bladeless (easier to clean and very safe for children). Some have remote controls. They are portable and good to help those within range feel cooler and range in price from £ to £££.

Caution: consider the cost of running the fan and the possibility that the engine itself may heat up the room further.

## Air conditioning

This is usually a large box that takes the air and makes that air cooler, thereby cooling the air in the room. Portable units are becoming more available, however you have to make sure the unit will cope with the size of the room and keep windows and doors closed (apart from somewhere to vent the machine). There has been some discussion within the EB community and clinical teams about whether these may dry out your skin and mucus membranes e.g. eyes. So, they are not always ideal with EB. Units are usually ££ to ££££.

Caution: check you have the space for a unit and consider the running costs.

## TOP TIPS

for keeping cool in the heat  
- for people living with all types of EB



**We have put together some suggestions for staying cool in the heat for people living with all types of EB. Many of these suggestions are tips that members have shared with us.**

- Stay hydrated. Keep a jug of water by your bed and another one in the fridge at all times. Ice lollies will also hydrate.
- Keep your moisturiser in the fridge and remember that water-based moisturising creams can be more cooling than oil-based ones, especially if you are applying to warm skin.
- Use a gel cooling cushion. To find examples try searching online for a 'chill pillow' or even puppy cool pads.
- Use cornflour on the soles of your feet and in-between the toes or in your shoes or socks to help absorb sweat.
- Use silver-fibred cotton or bamboo socks which conduct heat away from the feet.
- Wear light, ventilated footwear.
- Put your feet in a bowl of cold water especially before and after going out walking.
- Fill a hot water bottle or container wrapped in a tea towel with ice cubes or cold water and cuddle it or put it on your feet. NB: don't let your feet get too cold and make sure your skin is not in direct contact with ice.
- Run cold water over pulse points (if the area is free of wounds).
- Wet a thin scarf or piece of thin cloth and drape it over yourself like a sheet.
- Keep a set of spare underwear in a plastic bag in the fridge - especially socks.

- Keep a baking tray with a little water in it in front of a fan to maximise the cooling effect. Remember, don't direct a fan directly on to your skin as this can make your body think you are cold and then generate heat.
- You can get spray water cold mist in pharmacies, aimed at those going on hot holidays, to use when out and about.
- A fan can help you feel cooler by moving the air around you. There are many personal fans on the market that you can carry with you, including neck fans.
- Copy the Wimbledon champions and wrap plastic, bagged up ice cubes in a towel and place around your neck if comfortable for you and you have no wounds there.
- Make a note of where you can go locally that is air conditioned e.g. the cinema, shopping centre, café or library. Or places that may stay cool, such as historic buildings and places of worship.
- Heat rises, so if possible stay cool downstairs. Keep windows closed until it is cooler.
- Your GP, EB nurse or dermatologist may have further advice or contact our Community Support Team.

### DEBRA grants

If you live with any type of EB, you could apply for a grant for cooling items. To find out more about our support grant eligibility and how to apply, get in touch with your Community Support Manager to discuss your specific needs, or take a look at the support grant FAQs on our website here: <https://www.debra.org.uk/support-grant-faqs>

### Contact us

You can contact our Community Support Team for more information on 01344 771961 (option 1) or email [membership@debra.org.uk](mailto:membership@debra.org.uk)

Our Community Support Team work UK-wide to support members living with all types of EB and their families and carers. Find out more about the team and the range of support they offer by visiting the support section on our website.

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