



The South African Porphyria Foundation

SUN EXPOSURE

UV exposure is a trigger for variegate porphyrics.

Most will just call it SUN EXPOSURE, as this is where we find UVA & the dreaded UVB, but there is more to this trigger:

Not all patients suffers EQUALLY when exposed.

Not all patients suffers IMMEDIATELY when exposed.

UV rays can reflect, and can be present/high in a shadowed area on a cloudy day or under cover!!! Being out in the sun can cause variegate porphyria symptoms that ranges from:

- ➔ Pain, sensations of heat/burning (like a steam burn), blistering, skin redness, itching and/or as well as swelling.
- ➔ Fragile skin is a common symptoms after exposure. Sometimes even 3 days after, the skin can break easily, and inflammation sets in. These wounds can take up to 2 months to heal if the patient is in a smouldering state/attack.
- ➔ Blisters / sores heal slowly, often with scarring or skin color changes,(typically purple scarring) and may be disfiguring.

Not all variegate patients have the typical blistering as they may have tougher skins (olive skin), but can feel internal symptoms when spending time in the sun.

Depending on the duration and strength of exposure, the major symptoms include;

Headaches
Dizziness/fainting
Irritability/mood change
Abdominal pain
Nausea/vomiting
Shortness of breath
Flu-like joint/muscle pain

These symptoms can build up slowly and go undetected at first, or show within minutes of exposure.

Urine may become darkened, red or brown following an attack, but the said symptom does not necessarily have to be present.



Not all patients suffer the presence of typical port colour urine, but urine will be darker than normal.

The urine is also reported to have a distinct smell.

We cannot see UV rays, and the general rule of thumb is that it is where the sun touches.

THIS IS SIMPLY NOT TRUE.

Smooth / light / bright surfaces can reflect rays!

So being under an umbrella/roof/hat is not necessary safe for a variegate porphyric!!!
Something as simple as water, pale floor/sand, a white table cloth, snow or unprotected window can expose us to UV.