



# The South African Porphyria Foundation

## SMOULDERING PORPHYRIA

### Know the difference between:

- A “smoldering” state of Porphyria, which can be present over a long period of time, but leaves the porphyric in a chronic state of being unwell. Smouldering porphyria do not need an attack to activate the condition, and can leave a patient in a world of frustration.

### And:

- The symptoms of an oncoming attack. The smouldering symptoms will get more pronounced when a porphyric will go into an attack, but he /she might also develop new symptoms. These changes might be missed due to the fact that it becomes general knowledge that the patient are not feeling well and cannot do too much, and the support system becomes complacent that this is the state of affairs, while “getting on with it”.
- The patient is probably not aware that they are showing symptoms in the beginning. (Either in a smouldering state, nor an oncoming attack)

### Some common symptoms in smouldering porphyria are:

Agression, Anxiety, Paranoia,  
Depression  
Extreme/chronic Fatigue,  
Disorientation, Brain Fog/Forgetfulness,  
Itchiness, Hives-like rash,  
Clenching of the jaw,  
Poor / rapid loss of normal eyesight,  
Accute hearing and or sense of smell,  
Clumsiness / loss of balance / dizziness  
Pain in the joints, limbs/ fibromyalgia/ Flu-like aches,  
Shortness of breath/sleep apnea/deep or constant sighing,  
Holding of breath / sudden gasping for air  
Sugar- / carb cravings



Abdominal aches/ pain (often particular pains are recorded in woman as "side-aches" / pain in the flank(s), and in men the pain are often specified more in the middle-upper gut region, under diaphragm

PLEASE NOTE - this is merely an personal observation made through years of dealing with patients AND are common signs to look for.

(FROM: PORPHYRIA.DOC 08 PORPHYRICS ARE NOT LAZY / INDIFFERENT / UNINTERESTED!<sup>(L)</sup><sub>(SEP)</sub>)