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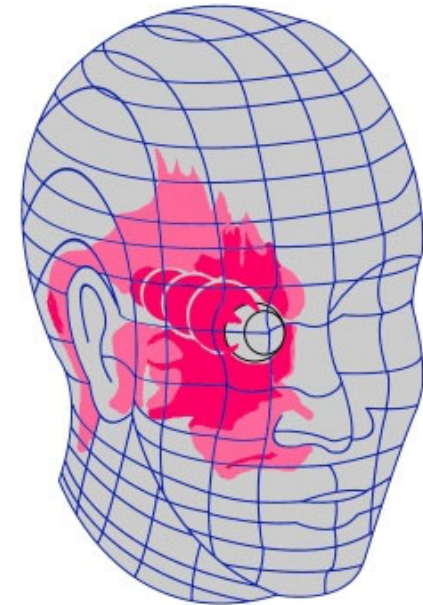
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Advice for Friends and Acquaintances of Cluster Headache Sufferers.

CSG

Clusterheadache Patient's group in Germany



Dear friends, family and acquaintances of cluster headache sufferers, your friend is suffering from a very rare and fiercely painful, incurable (but not life threatening) ailment known as Cluster headaches or Bing-Horton-Neuralgia. According to current knowledge it relates to a infection of the nerves close to the brain.

The sufferer experiences regular pain attacks of the most vicious severity which can not be compared to any other type of pain.

The best thing for most sufferers in the acute situation is to simply be left alone.

You cannot help them! The pain will automatically begin to wear off after a certain amount of time (a few minutes to a few hours). If the attack is very severe, the patient can help themselves either by inhaling Oxygen or injection of Sumatriptan. This will limit the length of the attack to a about 15 minutes. Usually following the onset of a severe attack the sufferers are simply exhausted, grant them some peace and quiet. When the attack is over the sufferer will return to your circle and you will barely notice what has happened.

After a long series of attacks the sufferers in many cases are very irritable and tend to be over sensitive. Imagine you had pain up to 8 times a day which feels like someone has put a hot poker in your eye and this happens over many weeks, you would also be easily irritated!

Therefore please think about your reaction, it would be fatal for the sufferer if he/she were to lose social contact due to the illness. And please show understanding when the sufferer appears late or cancels appointments altogether at short notice. Please think about the sufferer, it is also hard for him/her, they were also looking forward to seeing you.

In a CSG lecture about cluster headaches and social surroundings the following was described.:

It is not easy to live with a handicap, one's body, personality and private and work relationships are all very much affected. One experiences a reduction in the quality of daily life of which a "healthy" person could hardly imagine.

The health affects are often considerable, however, the suffering goes far wider.

- *one becomes depressed*
- *misunderstandings appear between friends and acquaintances*
- *so called friends withdraw, one would not be invited to occasions (she would only refuse anyway!!)*
- *and so on.....*

And suddenly one is all alone and asks oneself "what am I doing in this world??"

However, this fact should not be a reason to break all contact with people and withdraw from the outside world. Certainly it is very difficult when one has a lot of pain to exist normally but that would be the case for anyone in such a situation.

What is important is that we show ourselves and the outside world that despite our illness we have the will to continue, although we occasionally need a "timeout" period.

We have formed a new self-help group to make new friends and to work together to cope with the health, social and emotional problems

Such groups are now very wide spread and are recognised by the experts.

To sum it up, it can be said that to enable yourself to live with the chronic pain, it does not make any sense to simply surrender to the pain and give up.

Also it will not get you any further to just constantly fight against the pain, it is all too easy to forget the real world.

Please help your friend/acquaintance, do not leave a usually reliable friend isolated and out in the cold just because he has an illness..... (that basically he did not want or wish for)

How can you help friends and acquaintances?

Firstly you can be there for them, do not break contact or let the friendship dwindle. If you and your friend are a member of a club or group please accept that he/she may not always be able to attend events.

When sleep is reduced by one or two hours due to an attack, you can appreciate that sufferer would not be very interested in taking part in any sport or social events. However, the occurrence of the severe attacks phase only usually lasts for a couple of weeks - and then a few months later it all starts again.

There is certainly no reason to envy the sufferer!!

Be fair.... Who knows, at some time you too could be affected by this dreadful menace.

Through such means as this flyer, the CSG - Cluster headache Self-Help Group is trying to bring this suffering out in the open, to simply ensure that the sufferers of this hindrance are not left isolated.

If you would like to support us please contact the attached address where you will find out more.