#### Contacts:

Präsident:

Dr. Harald Müller, 41539 Dormagen Tel. 00492133478-484 harald.mueller@clusterkopfschmerz-selbsthilfe.de

Generalsekretär:

Jakob C. Terhaag, 52525 Waldfeucht Tel. 004924559309954 jakob.c.terhaag@clusterkopfschmerz-selbsthilfe.de

Vizepräsident:

Hans-Josef Liebertz, 50321 Brühl
Tel. 00492232931550
h.josef.liebertz@clusterkopfschmerz-selbsthilfe.de

Schatzmeisterin: Anja Alsleben, 48599 Gronau Tel. 00492562965-255

anja.alsleben@clusterkopfschmerz-selbsthilfe.de

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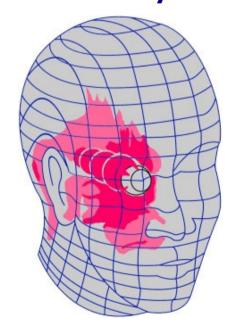
Tel. 0049 2455 / 9309954

www.clusterkopfschmerz-selbsthilfe.de www.clusterkopfschmerz.de www.clusterkopf.de

Für die Übersetzung dieses Faltblattes in die englische Sprache danken wir sehr herzlich Frau Kimberley Sadler Advice for Partners of Cluster Headache Sufferers.

**CSG** 

# Clusterheadache Patient's group in Germany



## My partner has been diagnosed as a sufferer of clusterheadaches. What does that mean to me?

Simply put, you could say that a cluster headache is a nerve infection in the head. It is not known where it comes from and according to current medical knowledge it is incurable..

Therefore, that means that you have to adapt to a life with a cluster headache sufferer.

That may seem a little shocking, however, it does not help anyone to give false hope of which noone can fulfil.

Your living conditions will change, as there will always be periods when the headaches appear more often and more intense than at other times. This is where the name "clusterheadaches" originates. When your partner suffers an attack, the most important thing is for you to stay calm. The attacks are indeed extremely painful and look very dangerous to onlookers, but they are in no way life threatening or in any other sense dangerous, just very painful.

Prepare yourself for the fact that the pain attacks over the years will be stronger and appear far more frequently than in the initial stages. Also, your partner will be woken in the middle of the night by a pain attack enough to drive him insane. He/she will be crying out with the pain. But also be clear that each attack will subside on its own after a certain time, usually between 15 mins and 3 hours.

Following consultation with your doctor, you should obtain oxygen with the relevant CSG flyer for the treatment of an attack.

Arrange your life so that the "sudden pain" is always taken into consideration. An attack could appear at any time...on the way to the cinema, during an evening with friends etc. But always be aware that despite your partners condition he/she is a completely normal person during the attack free periods.

#### How shall I behave when my partner has an attack?

As the partner of a cluster headache sufferer you have surely observed the extreme pain which your partner suffers with, the way the attacks simply appear and then after a certain amount of time also without treatment then disappear. There will still be some pain following an attack but this can usually be treated with standard painkillers.

Many sufferers report that they do not like to be pitied or mothered during an attack. As a partner, the important thing is to be prepared to help. The help could just extend to you running an errand e.g getting his/her medication or oxygen. It also helps a lot of people to have a cold compress, (sometimes offered in supermarkets as "Migraine glasses".)

It would be very advantageous for the sufferer if you were in a position to administer an subcutaneous injection as required with sumatriptan s.c. (trade name Imigran inject) In some cases a strong unsweetened coffee could be of good use. Pour your partner one if he chooses, but do not force him.

During an attack, avoid loud noises, (radio, tv, children playing), the sufferer experiences this far more extremely than under normal conditions. Also try to avoid arguments at least during an attack, it will be difficult enough for your partner to relate to you on a normal basis. And please try not to blame them for their illness "you always get an attack when we plan to go out!"

It has always shown that the best thing for a sufferer to have during an attack is peace and quiet.

### How do I make it clear to my friends that "I do not look after my partner when he is suffering"

If you are visiting friends or have friends over and then your partner has an attack, he/she is likely to want to retreat (so that he/she is not disturbed, so that you are not disturbed, so that he/she is not pitied etc) Give your partner the possibility of going to a separate room, try to help out by answering questions from inquisitive friends yourself and keeping such questions and friends "good advice" away from your partner.

Explain to your friends, preferably during the time when your partner is not experiencing an attack, that your partner suffers from an illness which at the moment is classed as incurable.

The illness is not life threatening but is extremely painful. Describe the pain for example as "having a red hot knife in your eye" or for friends who have children "like labour pains but in the head". Using both examples will give friends a good idea of what the sufferer experiences. Also explain to friends that it is not currently known what causes this neuralgia, that there are a few theories around but most of these just explain part of the illness e.g the accompanying symptoms.

As already mentioned, there is not a lot that you can do to help your partner during an attack. Try simply as far as possible to ignore the attacks (easier said than done!). Stay with your friends during an attack, say simply that "it is has happened again" and just be prepared to offer the help already stated in as far as that is possible when not at home.

Stay strong when your friends come out with such statements as "don't you want to help?" or "how can you stay so calm", try to fend off having to explain your actions.

There is a flyer available from the CSG especially for friends and family called Cluster Headaches and the Social Surroundings.

Order this sheet from us and hand it to your friends to read.