

PATIENT INFORMATION SHEET CHRONIC MIGRAINE

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Chronic Migraine

Chronic Migraine is a condition that may cause many different symptoms, usually including headache and/or facial pain. Patients usually experience some headache on at least half of the days each month.

Although headaches are often the most prominent feature of chronic migraine, some people experience relatively little discomfort. Some patients with chronic migraine present with other predominant complaints (e.g. chronic fatigue, neck or back pain, generalised body pains and tenderness, dizziness, vertigo, blackouts, poor memory and forgetfulness, excess sensitivity to noise or light, numbness down one side of the face or body, neck pain, exacerbation of irritable bowel symptoms, depression, irritability, etc.). In such people, it is important to recognise that features of chronic migraine are also present and that vigorous and appropriate treatment of this condition may provide significant alleviation of these symptoms.

A headache is typically described as “migrainous” if it has *any* associated features, e.g. nausea, throbbing, worsening by movement, or some degree of sensitivity to noise, light, or smell. Pain may occur *anywhere* in the head or face. It may also occur in the neck, back or other parts of the body. Only a small number of patients experience “aura” before or with their migraine. This may include visual disturbance, odd sensations, or difficulties with normal speech.

It is most usual for chronic migraine to start as “acute” individual attacks of migraine which gradually become more frequent over time. They may or may not become more severe. Typically the gaps between severe headaches fill in with milder intermittent migrainous headaches until there become relatively few days of the month where the head feels “brilliantly crystal clear” (with no pressure, tightness, aching, discomfort or throbbing, all day long). One of the most common features of chronic migraine is that medications to treat acute attacks have stopped working and there has been an escalation to different or stronger medications.

Additional symptoms are very common and may include fatigue, neck ache, odd sensory disturbance, twitching around the eye(s), feeling spaced out and dizzy, vertigo, insomnia, “restless legs”, short term memory and concentration difficulties, word finding difficulties, altered mood, and irritability.

Patients who develop “chronic” migraine are likely to have a genetic makeup that predisposes them to this condition. Features that may point to such genetic tendency to migraine include a history of :

- Other family members having experienced even rare migraine
- Previous or current travel sickness (e.g. including in childhood and inability to read or sit in the back of cars)
- Previous migraine in younger life
- Previous hangovers after just one or two alcoholic drinks (without actual intoxication)
- Irritable bowel symptoms

Certain factors may trigger a change from acute or chronic migraine and include hormonal changes, viral illness, stress, head injury etc. Often we can not identify a particular cause in individual cases. However, despite the initial trigger, it is most commonly the intake of painkillers and other acute attack medications⁽¹⁾ and/or caffeine ⁽²⁾ that keep it going. Even very small amounts may stop people getting better.

Foundations of management of chronic migraine

Successful management of chronic migraine involves laying down a good “foundation” of lifestyle. In other words, there is relatively little point treating with a migraine preventative drug if one has not done the basics. Like any foundation, it needs to be left in place long term!

The foundation of good management is:

No painkillers / acute attack medication
No caffeine
Good hydration
Regular meals
Regular sleep

The acute withdrawal of painkillers and caffeine

The best strategy in treating chronic migraine is to completely stop all painkillers and all caffeine as an *abrupt* withdrawal ⁽³⁾. Initially, this withdrawal typically causes marked worsening of headache over the first week or so. During this time it is important to maintain very good hydration and to prevent nausea and/or vomiting ⁽⁴⁾.

¹⁾This includes all drugs taken to alleviate headaches (e.g. paracetamol, codeine, tramadol, non-steroidal anti-inflammatory drugs (e.g. ibuprofen, voltarol), triptans, etc.).

²⁾ Caffeine is included in tea, coffee, cola, chocolate, Lucozade, Red Bull, Iron Bru, Dr Pepper, WKD and certain alcopops. Decaffeinated versions are OK to take in small amounts.

³⁾ If on very high doses of opiate medication, it is possible to take Clonidine to stop opiate withdrawal symptoms (protocol sheet for GP’s available via Walton Centre pharmacy).

⁴⁾ The most appropriate medication is usually Domperidone . The dose of Domperidone is 20mg orally up to four times daily as required for nausea or 30-60mg rectally up to twice a day in it’s place if there is actual vomiting. [Alternative anti-sickness drugs may have a potentially troublesome disadvantage of slowing gastric emptying and drugs such as buccastem, prochlorperazine, and cyclizine are probably best avoided].

If painkillers are used for other conditions, please see advice later in information sheet on “painkillers used for other conditions”.

As sleeping tablets may interfere with management and action of headache preventatives, it is best to avoid these if at all possible (See section below for information on sleep and migraine).

Once all painkillers and caffeine are stopped the headaches and other disturbance typically improves to some degree. If there are still headaches at this stage, we can then use a “preventative” medication that is taken on a regular basis, usually for one year. This preventative will often fail to help if caffeine or painkillers are still taken.

Lifestyle Measures:

In addition to stopping painkillers and caffeine, lifestyle measures are helpful both in the short and long term. The following lifestyle measures are recommended:

- drink plenty of clear fluids (e.g. 3 litres per day)
- avoid missing meals
- aim for 8-9 hours sleep at night, with the same time to go to bed and get up each day of the week where possible
- avoid daytime sleep and/or morning lie-ins

Preventative Medications:

I generally recommend a preventative medication if the headaches (or non-headache features of migraine) continue after withdrawal of caffeine and painkillers .

As already indicated, the commonest reason for headache preventatives to be unhelpful is if there is still continued use of any painkiller and/or caffeine.

The aim is to achieve 28 or more “brilliantly crystal clear headache-free” days per month.

Guide to use of preventatives:

- Unless otherwise indicated, I generally recommend that a headache preventative is taken for about one year, even if the headache settles much earlier than this. The rationale is to aim for a longer remission. At that stage the drug should be withdrawn very slowly over about 4 months.
- All preventative medications are slowly introduced in a stepwise fashion to a maximum tolerated dose, a maximum indicated dose or one that completely controls the headaches.
- If the drug causes persistent sedation (i.e. feeling sedated after being on a particular dose for more than a week), it should be reduced back one step. Sedation may stop the drug from working.
- Occasionally, drugs that are going to be effective in the long run cause *temporary* worsening of headache during the initial stages. This is actually a good sign and it is worth persevering for at least a few more weeks, possibly increasing the drug slightly more slowly.

- If the drug is not tolerated or has not helped at all after being on the maximum tolerated or maximum dose for 4 months, it should be gradually phased out (at same rate as introduced) and replaced at the same time with a different “2nd line” preventative drug.
- If a drug has had some benefit but not been wholly successful by 4 months of being on the maximum tolerated or maximum dose, it may be continued whilst another additional preventative is slowly introduced.

The drugs that we commonly use for migraine prevention may include:

1. **the tricyclic antidepressants** (e.g. dothiepin, amitriptyline, nortriptyline)
2. **the antihypertensives** (e.g. propranolol)
3. **selective serotonin reuptake inhibitors** (e.g. paroxetine, prozac)
4. **the antipsychotics** (e.g. olanzapine)
5. **the anticonvulsants** (e.g. epilim chrono, topiramate)

No drug that we use for any condition is entirely free of side effects or potential adverse problems. If you experience a worrying problem on a new drug it is advisable to consult your doctor or local pharmacist for advice.

You will see that none of these drugs are specifically called “antimigraine” drugs, as they were often found to be helpful in other conditions such as epilepsy or depression before they were shown to help migraine. However, at low doses, these drugs have all been shown to help significant numbers of patients with chronic or frequent migraine.

Other issues in management of chronic migraine

Previous prolonged aura

If in the past you have experienced a prolonged aura beyond 1 hour, you should not in future be prescribed Triptan drugs as there is a theoretical risk of stroke.

Painkillers used for other pain conditions

It is worth stopping painkillers even if used for *other* pain conditions such as arthritis, back pain, fibromyalgia, etc. This is because chronic migraine typically amplifies other types of pain. The mechanism for this amplification is called “central sensitization” and is the reason why migraines may amplify other normal sensations and make them less tolerable (migraineurs often experience central sensitization when they become less tolerant to loud noise, bright lights, smells, or experience odd sensations in their face, scalp or limbs). Most patients find that withdrawal of painkillers may initially exacerbate pain from these other conditions. However, with successful treatment of chronic migraine, this usually results in no long term worsening of these other pain conditions.

Other pain strategies may be suggested by your doctor. Common examples may include use of glucosamine and chondroitin for *arthritis* pain (it typically takes a month to start working).

Chronic back pain may be helped by daily extensor stretch exercises, Pilates stretch and relaxation classes, regular swimming. *Neuropathic (“nerve”) pain* may be helped by taking specific neuropathic pain drugs regularly. Some types of pain may be treated by one-off procedures such as nerve blocks.

Management of acute severe migraine attacks

Patients undergoing treatment of chronic migraine typically revert to having acute attacks. These may be frequent enough to consider a preventative drug. Sometimes they may occur despite a preventative drug. Advice for managing such individual attacks includes:

- Control for nausea – Domperidone 20mg up to 4 times per day
- Stop any vomiting – Use rectal Domperidone instead of oral preparation – 30 - 60mg up to twice daily
- Avoid anti-sickness drugs that reduce gastric emptying (e.g. buccastem, stemetil, cyclizine, etc).
- Over-hydrate at the beginning of the attack with 1 to 2 pints of water
- Local application of products such as menthol strips or “4head”
- Massage to the neck, temples or scalp
- Application of ice or heat packs
- Rest

There will undoubtedly be occasions where something more is needed (e.g. about to get on a plane to return from holiday, family wedding, exam, etc). I normally suggest that acute attack medication (e.g. painkiller + domperidone, or triptan drug) is strictly limited to such circumstances (but ideally no more than 4-5 times per year, and definitely less than once every month). By using acute attack medications more frequently, patients risk not only prolonging individual attacks but also loss of action of the lifestyle and/or preventative management strategy.

Sleep disturbance and migraine

Many patients with chronic migraine experience frequent waking throughout the night. Whilst this may be due to the migraine itself and will get better once the chronic migraine is properly treated, there may be other conditions that require their own individual management.

Sleeping tablets may interfere with the action of migraine treatments and should be gradually discontinued before starting migraine preventative drugs.

It is important to aim to go to sleep at the same time each night where possible and to avoid lie-ins or daytime sleep. It is important also to avoid drinks too close to bedtime and consider going to the toilet twice before bed if prone to passing urine at night.

Many patients seen in the headache clinic also have symptoms of *Restless Legs Syndrome* (RLS). In this condition, there may be discomfort in the legs and/or arms that is characteristically worse on sitting or lying at rest and relieved by walking around. Patients feel “compelled” to move their legs. They may wake with aching in their legs. Occasionally similar feelings may be noticed in the arms as well.

Many patients with this also twitch and move their legs in bed at night (*Periodic Limb Movements of Sleep*, PLMS) and wake with discomfort in their legs in the morning. Although this condition has not been formerly associated with migraine in the textbooks, I see this commonly in my headache clinics. Some patients find their symptoms worse in acute migraine attacks and the symptoms disappear with treatment of the chronic migraine. Others struggling to get better from their chronic migraine despite following the advice laid out in this sheet may benefit from treatment of these RLS / PLMS and can consult their doctor who could consider drugs such as Sinemet, Pramipexole, Adartrel or Clonazepam.

Another sleep disorder that may cause chronic migraine is *Obstructive Sleep Apnoea (OSA)*. Here, patients semi-wake many times a night because of snoring and stopping breathing. This is more common in patients who are overweight, have large necks or prominent breathing disorders. This can be easily diagnosed by being referred to a sleep clinic for overnight pulse oximetry and/or sleep study. Treatment with special breathing apparatus (CPAP) may have dramatic benefits.

Smoking and chronic migraine

The risk of stroke is increased in those with frequent or chronic migraine if they also smoke. This risk seems independent of the amount smoked and may be just as relevant to those who smoke only occasionally. The risk is particularly increased if you have (1) experienced previous aura symptoms such as distorted / blurred vision, odd sensory symptoms (e.g. tingling, numbness), or speech disturbance, or (2) had frequent headaches. Stopping smoking completely seems to gradually reduce this risk but it may take a couple of years to reach that of a non-smoker.

Exercise and chronic migraine

People who have chronic migraine often find they can not exercise because it exacerbates the headache. However, as we start treating this condition, it is very helpful to gradually increase exercise on a regular basis. This will be likely to help long term in keeping you as headache-free as possible.

Oestrogen-containing contraceptives

If you are female and have experienced migraine aura (distorted / blurred vision, odd sensory symptoms (e.g. tingling, numbness), or speech disturbance), it is advisable to avoid using oestrogen-containing preparations below the age of 50 years, as these may otherwise increase the risk of stroke.

Risk of migraine drugs and pregnancy

No drug is known to be 100% safe in pregnancy. The greatest risk is in the first few weeks of pregnancy (i.e. before pregnancy is realised or confirmed). If taking preventative drugs for migraine, it is strongly advised to take contraceptive precautions to avoid pregnancy. Some drugs are known to be associated with small increased risks to an unborn child and folic acid 5mg should also be taken in women of childbearing age.

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