

# Patient information from BMJ

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## Neuroleptic malignant syndrome

Neuroleptic malignant syndrome is a bad reaction triggered by certain medicines. The medicines are usually those used to control mental-health conditions such as schizophrenia.

Neuroleptic malignant syndrome (NMS) is a medical emergency that can cause death. If you or someone you know is taking the medicines discussed here, and develops symptoms of NMS, get medical help straight away.

### What is neuroleptic malignant syndrome?

Neuroleptic malignant syndrome (NMS) is a **medical emergency** that can be fatal. If you recognise the symptoms in yourself or someone that you know, get medical help immediately.

NMS is caused by a bad reaction to certain medicines. The most common cause of NMS is a reaction to medicines called **antipsychotics**. You might also hear these drugs called **dopamine antagonists**.

### Dopamine

**Dopamine** is a substance made in the brain. It is crucial to how our nervous system works. Dopamine has many jobs in the body. For example, it plays a large part in how we:

- send messages around the nervous system. For this reason it's called a **neurotransmitter**
- feel pleasure and happiness
- plan and think ahead
- get enough sleep, and
- control feelings of nausea.

Too much or too little dopamine can cause serious problems. For example, NMS happens when someone's dopamine levels are too low.

**Antipsychotics (dopamine antagonists)** can sometimes cause this to happen. These drugs treat conditions such as **schizophrenia** and **bipolar disorder** by reducing the amount of dopamine in the body.

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In people with these conditions, too much dopamine can lead to **psychosis**. Symptoms of psychosis can include hallucinations (seeing things that aren't there) and personality changes.

But if antipsychotic drugs reduce the amount of dopamine in the body by too much, it can cause NMS.

### Other medications and neuroleptic malignant syndrome

People taking medicines other than antipsychotics can sometimes have episodes of NMS. The most common ones are called **dopamine agonists**.

Although their names are similar and easily confused, these drugs are very different. Dopamine **agonists** do the opposite of dopamine **antagonists**.

They are used to treat conditions where people don't produce enough dopamine. They work either by increasing the amount of dopamine in the body, or by fooling the body into thinking that it has more dopamine than it does.

For example, they are an important treatment for **Parkinson's disease**.

NMS can affect someone with Parkinson's disease if:

- their dose of medicine is reduced too quickly, or
- they have suddenly stopped taking their medicine.

If you or someone you are caring for is taking either dopamine agonists or dopamine antagonists (antipsychotics), your doctor should carefully explain what NMS is, and what to do if you see the signs of it.

### What are the symptoms?

The main symptoms of NMS are the same whether they are linked to dopamine agonists or dopamine antagonists. They are:

- a fever
- stiffening of the muscles
- agitation, confusion, and other changes in someone's mental state
- increased heart rate, and
- fast breathing.

With dopamine antagonists (antipsychotics), symptoms usually start soon after someone starts treatment.

If you notice these symptoms **within three days** of taking one of these drugs, **get medical help straight away. NMS is a medical emergency that can cause death.**

With dopamine agonists, these symptoms can happen if someone (usually someone with Parkinson's disease) either stops taking their medicine, or reduces their dose too quickly.

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Again, if you notice these symptoms in someone with Parkinson's disease who is taking a dopamine agonist, **get medical help straight away**.

If you see a doctor who thinks that you might have NMS you will probably need to have some tests to find out. These might include:

- blood tests
- an electrocardiogram (ECG) to check your heart rhythm, and
- scans.

The doctor will also ask you (or someone with you, if you cannot communicate clearly for any reason) for a list of all the medicines you are taking. This helps to quickly find out which drug has caused the problem.

### What treatments are available?

This leaflet covers emergency treatment for NMS. But if you have an episode of NMS you will also need longer-term treatment to assess the ongoing drug treatment you need.

The **aims of emergency treatment** are to:

- restore dopamine to the right level in the body as quickly as possible, and
- treat the symptoms caused by NMS.

For NMS caused by **antipsychotics (dopamine antagonists)**, restoring your dopamine level means stopping the drug so that dopamine levels increase.

For NMS caused by **dopamine agonists** (usually in people with Parkinson's disease), this means restarting the drug or increasing the dose so that dopamine levels increase.

To treat the symptoms of NMS, the treatments you need might include:

- fluids to deal with dehydration. You might be able to take these by mouth. But some people need to be given fluids directly into a vein
- cooling you to get your temperature down. This might be done with fans or ice packs. Medicines that usually cool people when they have a fever, such as paracetamol, don't work for NMS
- sedative medicine to calm you and relax your stiff muscles. Relaxing your muscles helps you to breathe and swallow
- making sure you can get enough nutrition while you recover. If you are having problems swallowing, or if you are not conscious, this might mean having a feeding tube inserted through your nose, and
- oxygen if your stiff muscles are affecting your breathing.

### What to expect in the future

When you have recovered, your doctor will assess what medicine you need to start taking to keep you stable.

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For example, if you need to start taking an antipsychotic (dopamine antagonist) again, it probably won't be for a couple of weeks, just to let your body settle down. And it should usually be a different drug from the one that caused the problem.

Most people recover well from an episode of NMS. But about 8 or 9 in every 100 people die from it.

Some people have more than one episode of NMS. This is thought to happen to about 30 in 100 people who take medicines that can cause NMS.

NMS can't always be prevented. But being aware of the symptoms and getting help quickly when it happens give you the best chance of recovering.

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