MEDICINE INFORMATION

# Decitabine infusion (Dacogen)

Patient information about decitabine infusions, including treatment cycles, blood count monitoring and when to get help.

## At a glance

Decitabine is a medicine given through a drip for selected blood and bone marrow disorders. It is usually given on several days in a cycle, followed by time before the next cycle. Blood counts can fall, particularly early in treatment. Your team will schedule regular tests and tell you how to get help for infection, bleeding or increasing breathlessness.

**How it is given.** You receive decitabine as a drip into a vein.

## How it works

Decitabine changes how some genes are switched on or off in cells. It can help slow the growth of abnormal cells in the bone marrow, the soft tissue inside bones where blood cells are made. It also affects healthy blood cells, so your team will check counts throughout treatment.

## Is this treatment suitable for me?

The US label describes use in adults with certain myelodysplastic syndromes (MDS), where the marrow does not make enough healthy blood cells. European prescribing information describes use in adults with newly diagnosed acute myeloid leukaemia (AML) who are unsuitable for standard induction chemotherapy, the first intensive course. Ask why decitabine is being used in your plan and whether another medicine will be given with it.

This guide covers decitabine by drip. Tablets containing decitabine with cedazuridine have their own instructions. Ask your team to confirm the formulation and calendar.

## Before treatment starts

Tell the team about fever or recent infection, easy bruising or bleeding, liver or kidney problems and any medicines or supplements you take. The team checks blood counts, kidney and liver tests and may review the results of a bone marrow test. Ask for the emergency number, which hospital to go to and how to arrange blood tests between cycles.

## How treatment is given

You have decitabine through a drip into a vein. Treatment commonly involves consecutive days of visits, with a break before the next cycle. Different schedules are used, so follow the calendar your team gives you. Ask whether you will need a line, anti-sickness medicines or appointments on a weekend.

If you miss a visit, call the unit. They will review the timing of the remaining visits and tests. Report stinging, redness or swelling where the drip enters your arm.

## Monitoring your treatment

You will have blood tests between cycles as well as before treatment. Results help the team decide when another cycle can go ahead and whether you need blood products, treatment for infection or more monitoring. Your doctor may use repeat marrow tests, your symptoms and how often you need transfusions to assess response. A response can take several cycles.

## Side effects

### Common side effects

- **Low white cells.** These increase the risk of infection. Fever, a new cough, sore throat or discomfort when passing urine need prompt advice.
- **Low platelets.** You may see more bruises or small red spots, or notice bleeding from your gums or nose. Tell the team if this happens.
- **Low red cells.** Anaemia can cause tiredness, dizziness or breathlessness. Report a change so the team can check whether you need support.
- **Nausea, tiredness or bowel changes.** Ask what you can take at home and call if symptoms make it difficult to drink or eat.

### Important side effects

A serious infection may develop when counts are low. Counts can already be affected by the underlying disease, and symptoms can occur between cycles. Keep the hospital number available and tell emergency staff you receive decitabine. Bleeding can also become serious. If your team has told you your platelets are low, ask what precautions to take at home.

## When to seek urgent help

Call your hospital's 24-hour cancer care number straight away if you have fever, shaking chills, feel suddenly unwell, notice unusual bleeding or develop new breathlessness. Follow your hospital's temperature instructions. If you have no written threshold, call at 37.5°C (99.5°F) or above, or below 36°C (96.8°F). Call if you feel very unwell even without a fever.

Seek emergency care for severe breathing difficulty, chest pain, confusion, collapse, heavy bleeding or bleeding that will not stop. Tell staff when you last had decitabine.

## Practical advice for this treatment

### Prepare for several infusion days

Keep a calendar of infusion and blood test dates. Check where blood is taken between courses and how results are communicated if you have it taken locally. Ask about travel arrangements if multiple consecutive visits are difficult.

### Track symptoms between courses

Low red cells can cause fatigue and breathlessness. Low platelets may cause bruising, small red spots or bleeding. Note when symptoms begin and tell the team if they worsen. Arrange help if dizziness or tiredness makes cooking or travelling alone difficult.

### Discuss what can change the next cycle

Low counts can come from the illness or treatment. Your team may use blood tests, infection history and a bone marrow sample to decide if a delay, extra support or a different plan is appropriate. Ask who will call with changes to your appointment.

## Other medicines and vaccinations

Ask your team before adding medicines, vitamins or herbal remedies. Mention aspirin, anti-inflammatory painkillers and any prescribed blood thinners if your platelets are low. Ask about vaccines and the right timing for them during treatment.

## Everyday life

Make a plan for transport on consecutive treatment days. Keep a record of treatment dates, blood tests, transfusions and new symptoms. Ask who will call you about test results and when you should follow up if you have heard nothing. Keep a thermometer and the urgent advice number at home.

## Fertility, pregnancy and breastfeeding

Decitabine can harm a developing baby. Discuss effective contraception for you and your partner before starting and confirm how long it applies after the last dose. Ask about fertility preservation if relevant. Avoid breastfeeding during treatment and ask when it can safely resume for your exact product and plan.

## After treatment

Keep blood tests and follow-up visits until the team tells you what has changed. Bring a record of infections or transfusions to your review and check when to stop any preventive medicines.

## Frequently asked questions

### Is Dacogen the same as decitabine?

Dacogen is a brand name for intravenous decitabine.

### Is it the same as azacitidine?

They are different medicines that affect how genes are controlled in cells. Your team will explain why they chose your treatment.

### Are the tablets and drip interchangeable?

The tablets include another medicine that changes how much decitabine reaches the blood. Follow the instructions for your prescribed product and ask your team about any switch.

### Will I need to stay overnight?

Some people attend the day unit, while others need hospital care depending on their blood counts, symptoms or other treatment. Check your own schedule.

### What if I cannot come for one of the visits?

Call the unit before the appointment. They can tell you when to come and whether your tests should be moved.

### Why are blood counts checked during the break?

They can remain low or change between visits. Test results help the team decide whether you need support or a change to the next cycle.

### Can my counts get worse before they get better?

Yes. The disease and the medicine can both affect counts. Your team will look at the trend and other results.

### How soon can I tell if treatment is helping?

The team looks at changes in blood counts and may plan a repeat bone marrow test. It can take several cycles to judge the response. Ask when the team expects to review the results and what should prompt an earlier call.

### Will I need a transfusion?

It depends on your counts and symptoms. Some people receive red cells or platelets while waiting for counts to improve.

### Does a delay mean treatment has failed?

A delay can give the team time to treat infection or allow counts to recover. Ask what needs to change before your next visit.

### What if I get bruises or tiny red spots?

Call your team for advice. They may want to check your platelet count, particularly if you also have bleeding.

### Can I still see my dentist?

Tell the dentist and oncology team about your treatment and counts. Ask them to agree on timing before any procedure that may cause bleeding.

### Do I need to report a fever on a day without treatment?

Yes. Call the 24-hour number even during the break between cycles.

### What can I do if I feel too tired to manage my usual routine?

Tell your team so they can check for anaemia or other causes. Ask about practical support and plan rest around the tasks that matter most.

### What if my plan includes another medicine?

Ask for the names, the calendar for each medicine and any extra instructions for infection prevention or blood tests. This sheet describes decitabine by drip.

## Sources and further reading

Read this guide alongside your hospital’s plan. Ask your pharmacist to confirm the exact product dispensed in India and follow the instructions for that product.

### Summary of Product Characteristics (SmPC) and prescribing information

- Decitabine infusion (Dacogen) - EU SmPC
- Dacogen US prescribing information on DailyMed
- Dacogen UK Summary of Product Characteristics

### Additional sources

- MedlinePlus patient information on decitabine injection
- National Cancer Institute, decitabine

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