



Life Saving Drugs Program

Fact sheet for patients

About the program

The Life Saving Drugs Program (LSDP) pays for specific essential medicines to treat patients with ultra-rare and life-threatening diseases.

Most medicines in Australia are subsidised through listing on the Pharmaceutical Benefits Scheme (PBS). Funding for medicines on the LSDP is separate to the PBS.

The LSDP covers medicines if:

- they are clinically effective, but not cost effective enough to list on the PBS
- they treat life threatening and ultra-rare conditions (defined as 1 case per 50,000 people or fewer in the Australian population)
- the pharmaceutical company (sponsor) applies for an LSDP listing.

A list of the LSDP conditions and the medicines available for eligible patients are on the [About the LSDP](#) web page.

Because these medicines are critical for patients, the LSDP assesses all applications in less than 30 days. Most applications are processed by the LSDP in around 8 days.

How the LSDP works

Several groups of people work together on the LSDP.

- **Australian Government Department of Health and Aged Care** – funds and administers the program, and orders medicines to be supplied to the patient's nominated pharmacy.
- **Pharmaceutical companies**
 - apply to list eligible medicines on the LSDP
 - supply medicines to participating pharmacies.
- **Life Saving Drugs Program Expert Panel**
 - considers applications to list new medicines on the program
 - advises the Chief Medical Officer
 - reviews the medicines after listing.
- **Chief Medical Officer** – recommends to the Minister for Health and Aged Care if a medicine should be listed on the LSDP.
- **Treating physicians** – check if patients are eligible; prescribe the medicines; complete and submit application forms; complete the annual reapplication paperwork.
- **Pharmacists** (often at hospitals) – dispense medicines to patients according to the program rules.
- **Patients** – take the medicine according to their treating physician's instructions, and follow the program requirements for regular reviews.

Patient eligibility criteria

To be eligible for subsidised medicine under the LSDP, you must meet these criteria:

- Be eligible according to the criteria in the LSDP guidelines for your condition.
- Participate in regular assessment, as detailed in the guidelines. This helps the LSDP check how effective the medicine is. If you do not want to participate, you must have a valid reason.
- Not have any other medical condition that might make the medicine less effective. This includes complications of the disease that is being treated by the LSDP medicine.
- be an Australian citizen or permanent Australian resident who qualifies for Medicare.

Accessing medicine through the LSDP

If you are eligible, your treating physician will complete the relevant LSDP application form and send it to the LSDP.

Your treating physician must also send copies of all required test results as evidence of your condition. These results must be less than 12 months old.

Approval process

After your treating physician submits an application, it is checked for completeness by the LSDP and assessed to decide your eligibility for the program.

The LSDP will inform your treating physician of the outcome of your application within 30 days of submission of a complete application. Most applications are processed by the LSDP in around 8 days.

How your medicine gets to you

Once approved, the LSDP orders your medicine from the supplier. The supplier will ship your medicine to a hospital pharmacy, or other pharmacy of your choice, to dispense to you.

Because of the high cost of LSDP medicines, the LSDP orders only one month's supply of medicine at a time.

Picking up your medicine

Other people can pick up your LSDP medicines if required.

If your medicine is given to you in a hospital, suppliers can send LSDP medicines to the hospital pharmacy for dispensing to the infusion unit. This will happen just before you attend (as per hospital procedure).

Storing your medicine

Please ensure you store your LSDP medicine according to the instructions in the Consumer Medicine Information (CMI). Your pharmacist can give you the medicine's CMI leaflet.

If you do not store your medicine correctly, it may not be safe to use or may not work as expected.

If you have concerns about how your medicine has been transported, used or stored, please tell your treating physician immediately.

Changing hospital pharmacy

Contact your treating physician if you want to change your hospital pharmacy. Your treating physician must have prescribing rights for that hospital, and the nominated pharmacy must agree to manage LSDP medicines.

If the treating physician does not have prescribing rights at that hospital, they may arrange for a proxy to prescribe for them.

The treating physician must inform the LSDP of any changes, so your medicine goes to the new location.

Using a community pharmacy

You can use a community pharmacy if they agree to manage LSDP medicines according to the program's requirements.

Please speak to your treating physician if you want to use a community pharmacy.

Using the home infusion service

Please contact your treating physician if you want to start home infusions. Please note the home infusion service is not available for all LSDP medicines.

Costs

The Australian Government provides LSDP medicines at no cost to the patient. LSDP medicines are not part of the PBS, so PBS patient co-payments do not apply.

Your pharmacy might charge you a fee for cold transport and handling of your medicines as required. They must tell you about this cost up front and you must agree to it before the pharmacy dispenses the LSDP medicines. They cannot charge you any other co-payment or fee.

Annual reapplication process

Every patient receiving LSDP medicines must be reviewed by their treating physician and the LSDP each year. This makes sure that patients are:

- still eligible for the program
- taking the medicine as prescribed
- responding to the medicine in the expected way.

Each disease has different tests that a patient needs to have done each year. The LSDP guidelines for each disease state which tests are needed each year.

Your treating physician must send certain test results to the LSDP, along with a signed reapplication form showing you are still eligible for funding. If you have any concerns about why certain tests are needed, or how often, discuss this with your treating physician.

You must sign a privacy and data consent form **each year** as part of the reapplication process.

Your treating physician must send your reapplication to the LSDP by 1 May each year, unless the LSDP advises otherwise.

Your responsibilities under the program

To stay eligible for subsidised medicines through the LSDP, you must:

- continue to regularly see your treating physician during your treatment
- take your medicines as prescribed by your treating physician
- tell your treating physician as soon as possible if you experience any adverse effects while using your LSDP medicine
- take any required tests for reapplication each year
- (where applicable) store your LSDP medicine according to the instructions on the labelling or leaflet accompanying the medicine
- tell your treating physician if you believe your medicine is damaged in any way
- continue to be an Australian citizen or permanent Australian resident who qualifies for Medicare.

What you need to do if you want to travel

You will need your treating physician's authorisation to travel, if that travel affects your access to the LSDP medicine you are taking.

You must tell your treating physician the dates that you will be travelling. They must:

- ensure that you are fit to travel and will continue to meet the ongoing eligibility requirements of the LSDP
- tell the LSDP
- arrange for a treating physician at the new location
- ensure you understand that you might pay out-of-pocket costs when travelling.

Contact details for the LSDP team

Contact the department with enquiries about the LSDP.

Email: lsdp@health.gov.au

Telephone: (02) 6289 2336

Fax: (02) 6289 8537