

Rare disease medicine changes offer clarity

Proposed changes to the provision of medicines for rare diseases should bring greater certainty for people with these conditions, the Consumers Health Forum said today.

The Health Minister, Greg Hunt, in announcing the Government's response to a review of the Life Saving Drugs Program, says patients will be better supported by the proposed new process for listing drugs on the program.

"We welcome these changes which include expanding criteria for the consideration of funding for medicines which both extend a patient's life and improve quality of life for the patient," the CEO of the Consumers Health Forum, Leanne Wells, said.

"The proposed changes broadly align with what consumer groups said they wanted in the consultations which the Consumers Health Forum held to advise the review.

"Ensuring access to very expensive medicines for very small numbers of patients with rare and disabling conditions is a mark of the strength of Australia's pharmaceutical funding system.

"The changes will still mean that issues will arise concerning provision of these expensive medicines when they might not substantially or significantly extend life but would provide the patient with a better quality of life.

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Consumers shaping health

“Such circumstances might be covered by the provision within the new criteria for there to be provision of medicines offering noticeable decrease in disability as a result of the drugs.

“The challenges of reaching the right decisions in administering these medicines require strong and informed consumer advice.

“It is vital that consumers with lived experience and/or their carers are on the proposed expert panel to address the quality of life issue,” Ms Wells said.

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