

Tip Sheet for submitting Consumer Comments to the PBAC

About this Tip Sheet

This tip sheet is intended to assist people to make Consumer Comments to the Pharmaceutical Benefits Advisory Committee (PBAC). Consumer comments are generally most informative to the PBAC when you (or someone you know):

1. Are currently being treated with the medicine
2. Have been treated in the past with the medicine
3. Could potentially use the medicine in the future*

*Always check with your doctor if the medicine being considered is suitable for you

The only way the PBAC can understand what is important to patients is by hearing your story/personal experiences. Here are some tips to help you show how the medicine has helped you (or someone you know), and the impact it has had on daily activities and work.

FOR PATIENTS WHO ARE / WERE ON THE MEDICINE

What difference has this medicine made to your life?

If you were unwell before treatment, it is **really important** to describe the difference between how you felt then compared to now. Explain what those improvements have allowed you to do, see or feel and how it impacts your quality of life.

Use the tips below to show the difference the medicine has made to your symptoms, side effects, and quality of life compared to (a) before treatment with this medicine, and (b) other treatments you have tried.

Compare BEFORE & AFTER starting treatment:

- Use examples to describe the differences in how you felt *BEFORE treatment vs AFTER treatment*.
- Rate how different symptoms/categories were like BEFORE treatment by giving them each a number between 0 – 10, then rate how they felt AFTER treatment.

Example: Rate your pain levels (0/10 = no pain, 10/10 = extreme pain)

What were your pain levels BEFORE vs AFTER treatment? How has the pain changed? Are the levels constant, or does it come and go? Is the intensity different? Or more/longer times where you are pain free?

Example: Rate your fatigue (0/10 = no fatigue, 10/10 = extreme fatigue)

How long were your rest times BEFORE vs AFTER treatment? Do you need to rest less frequently now? Can you do daily tasks, or leave the house?

Example: Movement/exercise How much independent movement or exercise could you do before starting treatment compared to now? How far could you walk before needing rest/assistance compared to now? Compare the number of flights of stairs you could climb. Could you walk up hills?

Example: Episodes /relapses If your condition is episodic, has the frequency of episodes/relapses changed since beginning treatment? Have they been shorter? Or less severe? Are you having more good days & less bad days?

Example: Hospital visits Have you had less hospital visits since starting the treatment?

IMPORTANT What you don't need to include:

- a) **Research, statistics, test results.** The PBAC are provided with clinical trial results that demonstrate effectiveness.
- b) **Petitions to list the medicine because you or others need it.** The information you provide will inform the relevance of the clinical trial results presented to the PBAC. Patient relevance is one factor of many that the PBAC must consider before recommending a listing.

How to submit your comments

1. Online using the submission form

2. Email the PBAC directly:

CommentsPBAC@health.gov.au

3. Send a letter: PBAC Secretariat, MDP 952, Department of Health and Ageing, GPO Box 9848, Canberra ACT 2601

What does receiving this medicine mean to you?

Use examples from the list below, or add your own...

Level of independence

- Allows me to move freely
- Wash & groom myself
- Go shopping
- Drive a car safely
- Don't have to rely on others to do things for me

Home & family life

- Play with my (grand)children
- Contribute to home life
- Mow the lawn, gardening
- Be a role model to my family
- Prepare and cook meals

Social life

- Engage in social activities
- Attend functions
- Enjoy holidays
- Take my dog to the park
- Take up an old/new hobby
- Able to leave my room/house

Work & community

- Able to work/return to work
- An active member of the local community
- Do volunteer work
- Participate in community events
- Be a listening ear to friends

Emotional & psychological

- More motivated and positive
- Less frustrated/emotional
- More confidence
- Less depression/anxiety
- Feel stronger within myself
- Achieve the goals I set

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Explain the medicine's effect on your QUALITY OF LIFE:

- What have the changes or improvements meant to you?
- How this has changed everyday life for you?
- Use your **LIVED EXPERIENCE** to describe what difference this medicine has made to your life.
- What has this medicine allowed you to do, see or feel?

If you have responded to the medicine well, describe what this has meant to you? How this has changed everyday life for you? What can you do now that you couldn't do before? Do you have more independence, engage in social activities, still drive a car, mow the lawns, shop, or go to work? Or are you in bed most of the day because the medicine is making you feel unwell? Do you need care to help you shower, get dressed & feed?

Examples: Back doing things you love, back at work, going away on holidays, celebrate a special occasion, see the birth of a child, turn your dreams into a reality, your sports team winning a grand final, socialise with friends, or develop deeper connections with loved ones.

Compare your experience on DIFFERENT TREATMENTS:

- How did you feel on **PAST** treatments vs **THIS** treatment?
- How this treatment changed everyday life for you?

Example: Side effects Does this medicine have different side effects to other treatments you have used? If the side effects of past treatments (eg chemotherapy) were much worse than the ones you experience on this medicine, talk about what your quality of life was like at that time compared to this medicine?

Example: Medicine is taken in a different way Does this medicine have different form to other treatments you have used in the past (eg tablet instead of injection)? Do you need to take it less often (eg once a week instead of every day), or at a different time of day? Talk about the difference this made to your life.

Examples: more convenient, fewer doctor's appointments, less time off work, gives you more time to spend with family, allows me more flexibility so can travel away from home for longer.

What are the FINANCIAL IMPLICATIONS (Money)?

What is the financial impact of this medicine on you and your family?

If you have had to pay for this medicine, is this something you can realistically continue to do? What strategies have you had to use for you to pay for this medicine?

Examples: Fundraising Websites? Community fundraisers?

IMPORTANT

If you have **bad side effects** on this medicine, it's important to be honest about this, but also **say whether you have been willing to tolerate the side effects and why?**

FOR PATIENTS WHO DIDN'T RESPOND TO THE MEDICINE

Even if you are a patient who did not respond to the treatment as expected, you can write in and explain if there were any aspects of your health that improved while taking the medicine, whether this has allowed you to do more things and what impact this has had on your quality of life.

FOR FAMILY, FRIENDS & EMPLOYERS

The PBAC likes to hear many different perspectives so it can better understand the value of these medicines on the human life. This includes asking family members, friends and employers to write a submission. You may also want to sit with them and help talk them through this process.

It is important for them to talk about:

- What has it meant to them personally for you to have access to this medicine?
Examples: Contributions to the workplace and productivity, celebrate special occasions such as birthdays, Christmas/other religious events, go away on holidays together, help nurture your children, or your role as a grandparent.
- What benefits has the medicine had on you through **THEIR** eyes?
Examples: Allowed you to work xx hours per week, watched you sleep most of the day compared to now being more active
- How do they think this medicine has allowed you to continue to contribute to society?
Examples: Through charity work, employment, helping out within the local school etc
- In their opinion how has this medicine affected your **QUALITY OF LIFE**?
Examples: Are you able to still drive, do the grocery shopping, shower and dress yourself, wash the clothes, attend social functions, exercise, work etc?