

Tip Sheet for submitting Consumer Comments to the PBAC

About this Tip Sheet

You will be reading this Tip Sheet because you (or someone you know):

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

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

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

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

FOR PATIENTS WHO ARE / WERE ON THE DRUG

What difference has this drug made to your life?

If you were unwell before treatment, it is **really important** to describe the difference between that time and now, and the effect the drug has had on your life.

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

Explain what those improvements have allowed you do, see or feel.

IMPORTANT Don't talk about:

- a) **Data, statistics, scan results.** *The Government are provided with clinical trial results.*
- b) **Demanding the drug should be listed because you or others need it.** *The Government are more interested in knowing how well the drug works & the impact it has had on your life.*

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?*

How well do you live your life?

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

Tip Sheet for submitting Consumer Comments to the PBAC

Explain the drug'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 drug has made to your life.
- What has this drug allowed you to do, see or feel?

If you have responded to the drug 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 drug 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 drug 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 drug, talk about what your quality of life was like at that time compared to this drug?

Example: Drug is taken in a different way Does this drug 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 has 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 drug on you and your family?

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

Examples: Fundraising Websites? Community fundraisers? Re-mortgage your home? Sell your home?

IMPORTANT

If you have **bad side effects** on this drug, 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 DRUG

Even if you are a patient who has failed to respond to the treatment, you can write in and explain what it would have meant to you to have had a response - what you would have done with the extra survival time, had the drug worked more effectively?

FOR FAMILY, FRIENDS & EMPLOYERS

The Government likes to hear many different perspectives so they can better understand the value of these drugs 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 drug?
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 drug 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 drug 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 drug 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?