Financial Toxicity and Neuroendocrine Cancer

NeuroEndocrine Cancer Australia

Financial Toxicity in Neuroendocrine Cancer (NETs)

Financial toxicity refers to the financial burden individuals with neuroendocrine cancer may face. Studies conducted in Australia have identified that people living with neuroendocrine cancer experience higher costs related to **direct expenses** (medical tests, scans, appointments, and medication) and **indirect expenses** (travel to appointments, financial impacts like time off work).

Costs have increased over time, adding to the challenges for people living with neuroendocrine cancers who often live with the cancer for many years. Continuous financial assessment and support are essential throughout the course of their disease.

Financial Burdens May Include:

- High and ongoing out-of-pocket expenses
- Early retirement due to health and financial pressures – Employment and Cancer | NeuroEndocrine Cancer Australia
- Refusals of insurance coverage – it's important to review your insurance cover regularly.

Informed Financial Consent

You have the right to know all costs associated with:

- Doctor's fees
- Treatments
- Diagnostic tests and scans
- Medications
- Appointments

This information should be clearly explained and provided in writing before care begins.

Ask questions about costs with your doctor, hospital, or healthcare provider before consultations and treatments start. Informed financial consent means:

- Full financial disclosure
- Medicare reimbursement details
- Clear information about any gap fees

For more details and suggested questions, visit: Informed financial consent | Questions to ask your HCP | Cancer Council Australia.

If You Receive an Unexpected Bill:

1. Contact the provider for an explanation
2. Check your insurer (if you have private insurance) and Medicare details
3. Request a review or itemised bill - An itemised bill should show individual service descriptions, applicable MBS item numbers, and separate contact details for any other providers who will bill you separately (e.g., anaesthetists or pathologists).

If unresolved, contact:

- Health and Disability Services Complaints Office
- Care Opinion Australia
- Health Consumers' Council in your state for advocacy support

Pharmaceutical Benefits Scheme (PBS)

- The PBS is an Australian Government program subsidising prescription medicines for Medicare card holders.

To access subsidised medicines:

- Present your **Medicare card** and a valid doctor's prescription at the pharmacy Medicare - Services Australia.

Costs may be reduced or waived if you:

- Hold a **Commonwealth concession card** (e.g., Pensioner Concession Card or Health Care Card) Concession and health care cards - Seeking medical help - Services Australia

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- Qualify for the **PBS Safety Net** Pharmaceutical Benefits Scheme (PBS) | Frequently asked questions;

Not all medicines are listed on the PBS or subsidised for every condition. In some cases, patients may need to pay the full cost of a medication or meet specific eligibility criteria to receive a subsidy. If a prescribed treatment is not PBS subsidised, discuss the available options, costs, and any alternative treatments with your doctor or healthcare team.

Being informed and proactive about financial aspects of care can help manage the financial impact of NETs effectively.

Further Support

NeuroEndocrine Cancer Australia: Wellness Wednesday Fact Sheet on Financial Toxicity - https://neuroendocrine.org.au/wp-content/uploads/2026/05/Wellness-Wednesdays-Fact-Sheet-Financial-Toxicity.pdf

Cancer Council: Financial costs and assistance - https://www.cancer.org.au/support-and-services/financial-assistance

Financial Counselling Australia: Free, confidential financial counselling service. 1800 007 007. https://www.financialcounsellingaustralia.org.au/

Financial Information Service (FIS): Free, confidential service from the Department of Human Services to help with investment and financial decisions. 132 300 (say 'Financial Information Service') - https://www.servicesaustralia.gov.au/financial-information-service

MoneySmart: Free financial tips and safety checks from the Australian Securities and Investments Commission (ASIC). 1300 300 630 - https://moneysmart.gov.au/

Government benefits

Department of Human Services (Including Centrelink and Medicare): Financial support for people in need. 132 717 - Centrelink. 132 011 - Medicare. https://www.servicesaustralia.gov.au/health-and-disability

Pharmaceutical Benefits Scheme (PBS): Helps with cost of prescription medicines. 1800 020 613. https://pbs.gov.au/home.

Bankruptcy

Australian Financial Complaints Authority (AFCA): Free, independent service for resolving disputes with financial services. 1800 367 287 - https://www.afca.org.au/

Australian Financial Security Authority (AFSA): Information about bankruptcy and personal insolvency agreements. 1300 364 785. https://www.afsa.gov.au/

Telecommunications Industry Ombudsman (TIO): National independent dispute resolution scheme for complaints about phone or internet services. 1800 062 058. https://www.tio.com.au/

Legal Advice

National Association of Community Legal Centres (NACLC): The peak national body for Australia's community legal centres, which provide free legal services. 02 9264 9595. https://clcs.org.au/

No Interest Loan Schemes (NILS): Support to access the essentials you need now, with no interest and affordable repayments.13 NILS (13 64 57). https://nils.com.au/

Taxation Australian: Taxation Office Tax information. 13 28 65. https://www.ato.gov.au/

If you need further support or information about neuroendocrine cancer, contact the **NET nurses at NeuroEndocrine Cancer Australia on 1300 287 363** Monday-Friday 9am-5pm