



**NeuroEndocrine
Cancer** Australia

Treatment

Symptom Management, Watchful Waiting,
Palliative Care and Prognosis

Symptom Management

Telotristat etipirate (Xermelo)

Telotristat is a novel oral drug. It inhibits an enzyme that is responsible for the production of serotonin. Excessive blood levels of serotonin cause carcinoid syndrome (diarrhoea, flushing, abdominal pain); therefore, decreasing its production can reduce these symptoms. The recent TELESTAR trial enrolled patients with carcinoid syndrome and 4+ bowel movements per day. The patients who received telotristat reported significantly fewer bowel movements. It is worth noting, however, that telotristat improved bowel motions by approximately 1/day over placebo i.e. patients on telotristat may still have multiple bowel movements per day. Urinary 5-HIAA (reflecting serotonin production) was also reduced with telotristat. This is a promising option for treatment of patients who have diarrhoea from carcinoid syndrome despite SSAs.

This drug does not act on the tumours to control their growth.

Watchful Waiting

No treatment, or watchful waiting, may be the best option for some NET patients especially if the NET is not causing symptoms or problems, the disease is stable, or the tumour is low grade (G1).

For some people, poor general health or complications secondary to treatments may also make further NET treatment inadvisable.

Palliative Care

Involving Palliative Care team members as part of the multidisciplinary team is extremely beneficial from diagnosis onward as this can improve the patient's and family's quality of life psychologically and physically. Palliative care is care that helps people live their life as fully and as comfortably as possible and provide services which can meet the individual needs by –

- Relief of pain and other symptoms e.g. vomiting, shortness of breath
- Resources such as equipment needed to aid care at home

Palliative Care *(continued)*

- Assistance for families to come together to talk about sensitive issues
- Links to other services such as home help and financial support
- Support for people to meet cultural obligations - Aboriginal and Torres Strait Islander (ATSI), Cultural and Linguistic Diverse (CALD) populations and preferences
- Support for emotional, social and spiritual concerns
- Counselling and grief support
- Referrals to respite care services

Please refer to www.palliativecare.org.au for further information

Prognosis

Many patients have an excellent prognosis from NET. If low-grade disease is completely cut out (resected), there is a good chance that it will not come back. However, these patients may need follow-up over a long period to monitor for recurrence.

Even for patients with advanced (unresectable) disease, there can be a wide range of outcomes. The average outcome is quite dependent on the histological (tissue-based) grade of the NET. Patients with low-grade (Grade 1) disease may survive for many (even 10+) years. Patients with high grade (grade 3) disease that is aggressive have an average survival time measured in the range of many months to a few years, despite best treatment.

It is important to realise two things about prognosis:

1. There is a big variation in prognosis - there is a lot of variation in outcomes and no “magic number” for a particular patient. Some patients find discussion of ranges in prognosis (best case/worse case/expected scenarios) very helpful.
2. New treatments and insights can improve care and hence prognosis for all NET patients. Therefore, prognoses based on the available information are a rough estimate.



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