HEALING EFFECTIVE COLLABORATION ON A NEUROENDOCRINE CANCER GUIDE FOUNDATION Navigating the NET Patient Journey: Valuable Insights and Resources for Living with Neuroendocrine Cancer

BACKGROUND

A diagnosis of neuroendocrine cancer triggers fear, and the terminology alone confuses patients living with this rare cancer. In 2019 the Healing NET Foundation convened a *joint task force of* physicians, APPs, patients, and caregivers to explore patient-physician communication and ways to improve the patient experience.

High priorities for patients, as identified by the task force:

- finding accurate and trustworthy information
- receiving appropriate assessment, treatment, and monitoring

The group's top recommendation to address patient needs was to develop a patient "primer" with reliable, vetted information.



PROCESS BY ROLE



TASK FORCE

The task force reviewed materials already in existence. While detailed medical information was available through other sources, little was available from the patient perspective on navigating this rare diagnosis. The group, in coordination with Healing NET Foundation staff, decided to focus on creating a roadmap to the patient journey that acknowledged the uniqueness of the journey for each person.



CONTRIBUTING AUTHORS

The patients and caregivers on the task force--who serve as support group leaders and advocates—took the role of contributing authors. One of the contributing authors bridges perspectives as both a caregiver and a nurse practitioner. The lead author/editor chosen from within the group has a background in social work.



STAFF

Staff helped coordinate the writing process, were involved in editing, and planned publication.



CONTRIBUTING EXPERTS

The "contributing experts" group included physicians, a nurse, and a hospice chaplain. They reviewed medical information and provided supplemental commentary.



PATIENT FOCUS GROUP

A patient focus group that included HCPs reviewed the final draft and gave valuable feedback.

FINDINGS

Time

Writing as a group took longer than expected.

Stakeholder Involvement

Involving multiple stakeholders yielded a document that is inclusive and comprehensive.

• As support group leaders, the authors represented a much broader set of experiences than just their own.

• The medical expert perspective helped clarify expectations around care and lent authority.

 A focus group of patients added clarity and made the publication more user-friendly.

Lead Writer

Establishing the role of lead writer/ editor created an efficient interface with the authors and with the Healing NET staff. The point person had responsibility for harmonizing the disparate writing styles, making decisions about chapter organization, and adjusting the level of detail in the different chapters.

Patient Voice

Capturing the patient voice not only helped patients relate but also helped HCPs better understand what patients with this rare disease go through.

Early in the process, plan how to promote and distribute the resource. Set up systems to track delivery and to gather feedback on usage and value.

Establish roles of each participant.

Agree on a timeline that allows for the full process. Coordinate and communicate any changes.



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RECOMMENDATIONS

Involve Multiple Stakeholders

Involve multiple stakeholders when developing materials for patients and caregivers.

Clarify & Research

Clarify the need and research what is already available to avoid duplication.

Plan Early for Later Stages

Establish Roles

Coordinate & Communicate

AUTHORS

