

Empowering Caregivers of Pancreatic Cancer Patients for Enhanced Patient Outcomes (EC for EPO)



2018 'ImpactPANC' Award for Innovation

1. Overview

Records show 80 new cases of pancreatic cancer in Cyprus every year out of which 80 percent are diagnosed when the disease has metastasized and is difficult to be treated. Psychosocial support is of paramount importance for both the patient and caregiver, from the moment of diagnosis throughout the pancreatic cancer journey up to rehabilitation and/or bereavement.

The Cyprus Association of Cancer Patients and Friends, PASYKAF provides psychosocial support services free of charge to cancer patients upon referral. This initiative will focus on evolving psychological support within group settings for pancreatic cancer caregivers.

Additionally, over 80 percent of pancreatic cancer patients report weight loss when diagnosed, and suffer from malnutrition due to physiologically-induced anorexia, malabsorption and increased caloric requirements. Oncology Nutrition Expert Services are not available by the Cyprus NHS yet, except for a limited provision in one Oncology Centre and the private sector.

2. Objectives

Psychosocial Caregiver Support Group Programs

- Existent one-to-one support to be complemented with group support for caregivers and patients, during and post therapies, to enable individuals to share personal experiences, feelings and coping strategies.
- Existent Bereavement Support Groups aiming to provide information and psychological tools to individuals who have experienced the loss of a loved one
- Caregiver workshops

Expert Nutritional Guidance

An Oncology Nutrition Expert will:

- Consult pancreatic cancer patients and train caregivers
- Provide practical guidance regarding nutritional problems
- Redress symptoms and address caregivers' and patients' needs

3. Methodology

The patient referral system from the Oncology Centre, private hospitals and clinics and public hospitals to PASYKAF has been running for several years.

PASYKAF's social workers team will receive the pancreatic patient's referral from their doctor asking to be offered one of PASYKAF's free services (psychosocial support, home nursing/palliative care, physiotherapy, transportation and rehabilitation).

In addition, PASYKAF's social worker will assess the patient's and the caregiver's overall needs and forward the patient details to the desired service/health care team.

Oncology Nutrition Expert Guidance is not yet considered to be one of PASYKAF's services as it is only administered to pancreatic patients and caregivers at this point. For this reason, it is not included on the referral form, but doctors will be informed about this service as well as PASYKAF staff. All pancreatic patient referrals will be forwarded to the Oncology Nutrition Expert Guidance and Psychosocial support team for assessment.

4. Outcomes.

Caregivers will be provided with:

- Tools to administer the best possible care including advice on diet, treatment schedules and practical day-to-day routine.
- Help to restore mental, physical and psychological balance...
- Secure optimum quality of life with the reliable support network of PASYKAF.
- Confidence and empowerment

Pancreatic cancer patients:

- Concerns about post-operative nutritional care will be addressed with a personalized nutritional plan.
- Nutritional support and consultation by the Nutrition Expert will help minimize symptoms such as loss of appetite, nausea and vomiting and control weight loss.
- Home-stay decision during the end of life stage will be enhanced.

This initiative may long term help:

- Encourage support groups to flourish.
- Oncology Expert Nutrition Guidance to gain a place among the oncology health professional team.
- National Health System adopt this approach as a standard procedure.
- Introduce best practices for nutritional screening to be performed at the time of the diagnosis, not later.

5. Measurements, Impact and Timeline

Standard evaluation measures will be used on a continuous and periodic basis.

Psychosocial Caregiver Support Group & Expert Nutritional Guidance Programs will be assessed by:

- Completion of appraisal forms anonymously.
- Caregiver Quality of Life questionnaire to highlight their needs – emotional, psychological or physical.
- Caregiver workshops will give more recognition to their role and provide documentation on how their needs should be measured to help solve several of the problems faced.
- PASYKAF's database system will be used to keep patients' records.
- Portable device for Bioelectric Impedance Analysis will be used to capture body composition data (body fat, visceral fat, muscle mass, muscle quality, total body water, bone mass, physique rating, basal metabolic rate, daily caloric intake, body mass index). This will be recorded in a separate database system under each patient's personal file.
- Patient's personal file will also include: record of advice and support given to caregiver at each session, clinical examination details and weight records.
- Malnutrition Universal Screening Tool (MUST)
- Telephone communication with PASYKAF's officers will be available for pancreatic cancer caregivers/patients for any concerns or additional information needed.

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