## WP8 : Survivorship and Rehabilitation

#### **Stakeholder Forum – WP8**



Rome | 15 September 2016



# INTRODUCTION

The following recommendations are :

- Draft recommendations;
- Highlights of key messages that WP8 will disseminate;
- The result of a large consensus amongst WP8 partners and experts.





## RECOMMENDATIONS FOR QUALITY IN SURVIVORSHIP CARE

1. An early and personalised follow-up program should be systematically planned and delivered to each survivor:

- Adequately assessing the survivors' individual risk of multidimensional late effects of treatment and respective rehabilitation needs (e.g. physical, psychological, social, cognitive, sexual, nutrition, etc.)
- Creating opportunities for socially disadvantaged people to fully engage in follow-up programs.

2. Adequate and updated information on medium and long term effects of treatments should be available to survivors and their relatives, as well as to care providers involved in the follow-up, in particular primary care professionals, for a better prevention and care.





## RECOMMENDATIONS FOR QUALITY IN SURVIVORSHIP CARE

3. Identification and management of late effects of cancer treatment should be integrated in the professional training and continuous medical education of clinicians (including general practitioners).

4. In tertiary prevention, self-management should be emphasized, particularly on lifestyle recommendations and on the risks of long term effects :

- Smoking cessation;
- Weight control and healthy diet including limited alcohol consumption;
- Sufficient sustained physical activity;
- Avoidance of excessive exposure to UV-radiation.
- Stress management

5. Physical activity should be integrated early in the care pathway for all cancer survivors. It should be an important component to consider at every phase of survivorship care for all survivors in order to maintain healthy life-style.





## RECOMMENDATIONS FOR QUALITATIVE REHABILITATION INTERVENTIONS

# 1 - The evaluation of the physical and psychosocial rehabilitation needs should first be screened as follow:

- The baseline screening should be performed prior to the start of any cancerspecific treatment

- Both physical and psychosocial screening should be carried out simultaneously by using simple algorithms; for physical screening at least the following items should be screened: cardiac function, muscle strength and flexibility. For psychosocial screening, please refer to the assessment framework.

- After the first screening regular updates should be performed on individual basis.





#### ASSESSMENT OF SYMPTOMS AND NEEDS FOR A TAILORED ORIENTATION AND INTERVENTION IN PSYCHOLOGICAL SUPPORTIVE CARE

Why? The purpose of a qualitative assessment of symptoms and needs in cancer settings is about:

- improving the quality of health care (targeting each patient's needs and directing resources to optimize patient's clinical outcomes);
- improving clinician-patients communication;
- regularly monitoring physical, social and psychological functioning to take better address these needs.

The qualitative assessment of symptoms and psychosocial needs is not only useful for the orientation towards adequate care interventions but also for the patients themselves who increasingly express their interest of being involved in their supportive care pathway.

When? Symptoms and needs must be assessed as early as possible and at every "step" of the cancer journey: diagnosis, treatment, rehabilitation, follow-up, and end of life.

Who? The qualitative assessment of symptoms and needs should apply to all cancer patients and survivors. Healthcare professionals should incorporate the detection of patient reported outcomes in their routine clinical activity.

What? Qualitative assessment of symptoms and needs should cover:

- physical aspects (functional assessment and symptom burden),
- social aspects (family, relational, employment issues),
- psychological aspects (emotional, spiritual, sexual),
- perceived barriers to care,
- satisfaction with cancer care.

How to assess? Tools and measures should be defined at a local level, but they should share common characteristics agreed at the European level. They should be:

- very brief;
- validated in the local language (patient's language);

- good performance parameters: validity; reliability; sensitivity; specificity; positive predictive value.





## RECOMMENDATIONS FOR QUALITATIVE REHABILITATION INTERVENTIONS

2 - Periodic screening of psychological distress and psychosocial needs should be conducted during the entire cancer pathway by the health care professionals (*e.g.* oncologists, physicians, and nurses) and integrated in routine cancer care; this screening will be followed by adequate provision of psychosocial care.

3 - For the diagnosis of psychological conditions the assessment should be carried out by a psychological care professional.

4 - Psychosocial interventions in individual or group format should be delivered by appropriately trained professionals with specific expertise in psychosocial oncology





## RECOMMENDATIONS FOR QUALITATIVE REHABILITATION INTERVENTIONS

5 - Social and return-to-work issues should be integrated early into the cancer care pathway. The adaptation of the working conditions for any patient returning to his/her previous work should be assessed at early stages.

6 - Cancer survivors' working lives, their employability, skills and capacity to work, as well as their motivation to work should be safeguarded ;





# RECOMMENDATIONS FOR THE MANAGEMENT OF S & R CARE

1- The role of GPs and other primary care professionals should be actively supported to help them manage all the care plan challenges. Their role should be clearly defined and tailored to the patient and the care plan needs.

2 - After the completion of the acute treatment phase, the follow-up period should begin with the elaboration of a survivorship care plan (SCP).

**3 - Communication between primary healthcare providers and healthcare specialists needs to be improved**. Electronic patient records systems (EPRS) should be accessible to all healthcare providers treating the patients.





# RECOMMENDATIONS FOR THE MANAGEMENT OF S & R CARE

4 - A key health care professional assuming a case management role should be assigned to each patient in accordance with medical and/or psychosocial specific requirements. This health care professional could play a main role in reducing the vulnerability of patients.

5 - Empowerment of patients and their relatives should be enhanced to increase their participation in self-management, rehabilitation and back to work programs. Online programs would facilitate this process.





# Survivorship Care Plan (SCP)

- A SCP should be delivered to all patients following a multidimensional needs' assessment and this SCP should be tailored and updated regularly according to the patient's health conditions.
  - After the completion of the acute treatment phase, the patient should be given a survivorship care plan (SCP) that would contain:

- baseline information on the personal and medical profile of the patient (ID, age, summary of the treatment received), with additional data or possible late and long-term effects and medical history;

- a minimum set of tailored supportive care services consisting of pain management and psychological support for patients and their relative against anxiety and depression. Healthy lifestyle issues (including e.g. tobacco cessation, physical activities, nutrition and weigh management, beauty care) as well as sexuality and fertility support should also be considered;

- social support and professional rehabilitation services.

- The survivorship care plan (SCP) should be elaborated and implemented by the MDT composed of:
  - an oncologist in collaboration with other professionals plan the follow-up process;
  - a general practitioner (GP) who deals with the impact of cancer and its treatment of the general health;
  - a (specialist) nurse or a support worker who is in charge of coordinating follow-up care amongst all services providers involved;
  - a community care centre which deliver information, educational activities about survivorship care.
- From a technical point of view, in order to meet its communication and care coordination objectives, the SCP should be:
  - accessible to all health care professionals having therapeutic relationships with the patient;
  - updated regularly;

- using a format that optimize the understanding and the communication of information between patients and health care providers (and amongst health care providers).





# Thank You





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