



EUROPEAN
CANCER
PATIENT
COALITION

ESMO-ECPC Cancer Survivorship Guide & Cancer Survivorship Plan

A unique care and cancer advocacy tool

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EUROPEAN CANCER PATIENT COALITION

NOTHING ABOUT US, WITHOUT US!



ECPC: The patient voice in Brussels

Background	ECPC Action
<ul style="list-style-type: none">• Advocate against social stigma• Support implementation of CanCon recommendations on Survivorship• Cancer is a public health but ALSO a social-economic issue	<ul style="list-style-type: none">• Active involvement in JA CanCon recommendations for cancer survivorship• ECPC-ESMO Guide for Cancer Survivorship

European Joint Action for Cancer Control

CanCon

- **CANCON:** EU funded joint action of 17 EU associate member states and 65 collaborating partners for the development of guidelines for the harmonization of the national cancer plans for cancer control
- **WP 8: Survivorship and Rehabilitation** developed a high quality European framework for survivorship and rehabilitation
- **Recommendations of WP8:** they cover all aspects and all areas of cancer control from diagnosis to psycho-social rehabilitation.
 - Based on the patients needs and condition
 - Recommendations of cancer policy supporting health systems sustainability and adoption by all member States, with emphasis on rehabilitation and employment

ECPC – ESMO Memorandum of Understanding May 2016

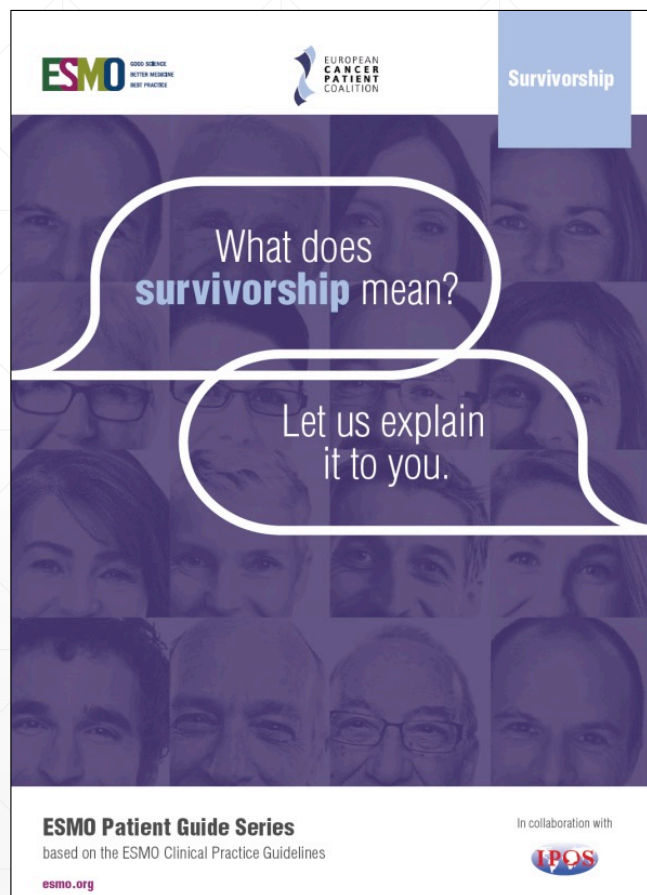
- Strengthens existing collaboration among ECPC and ESMO
- Practical collaboration on concrete topics:
 - Update of ESMO Guidelines
 - Update of ESMO Patient Guides
 - Creation of Survivorship Guide and survivorship care plan



Survivorship Guide

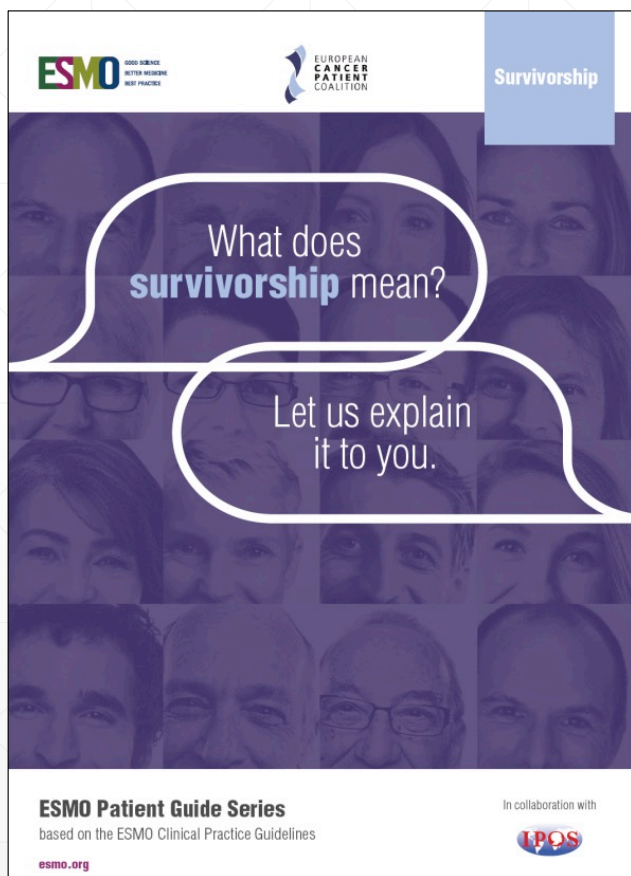
Created by ESMO & ECPC

in collaboration with International Psycho-Oncology Society



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Defining Survivorship



Survivorship Care is about

- follow-up and late years care
 - management of late effects of cancer care
 - improvement of quality of life
 - sound psychological & emotional health
-

Content of the Survivorship Guide

- Practical recommendations

- Survivorship Care Plan

- Glossary

- Support in coping with the new reality - Who can help me?
- Life after initial treatment - How can I get my normal life back?
- Preventive health - What lifestyle changes can I make to achieve optimal physical and emotional health?
- Follow-up care:
 - Detection and management of treatment- or tumour-related symptoms
 - Prevention and detection of cancer recurrence
 - Prevention and early detection of new primary cancers for patients and their family members
 - Comorbidities and management of comorbidities
 - Keeping a personal health record / Survivorship care plan

Survivorship Care Plan

*the connection between patients,
medical oncologists and GPs*



Survivorship check list, care plan and treatment summary

Background information

YES NO

Family history of cancer

☐ ☐

Genetic/hereditary risk factor, predisposing conditions:

Genetic counselling:

☐ ☐

Genetic testing results:

Fertility: cryopreservation

☐ ☐

Diagnosis

Cancer type and location:

Date of diagnosis (year):

Stage:

☐ I ☐ II ☐ III ☐ IV ☐ NOT APPLICABLE

Method of diagnosis:

- Imaging tests
- Laboratory tests
- Biopsy
- Site of biopsy:

☐ ☐
☐ ☐
☐ ☐

Treatment

YES NO

Surgery

☐ ☐

Surgical location, findings:

Surgery date:

Radiation therapy:

☐ ☐

Radiation date:

Radiation area:

☐ Chest ☐ Abdomen ☐ Pelvic area
☐ Head and Neck ☐ Testis ☐ Breast and Axilla
☐ Other area (i.e. extremities)

Systemic therapy (Chemotherapy, hormonal therapy, immunotherapy, targeted therapies)

Type of therapy:

☐ Chemotherapy ☐ Hormonal therapy
☐ Targeted therapies ☐ Immunotherapy
☐ Combination

Name of drug	Therapy start date	Therapy end date

Symptoms and side effects during therapy

Fatigue

☐ Nausea and Vomiting

☐ Pain and peripheral neuropathy

Sleep disorders

☐ Skin and soft tissue problems

☐ Loss of appetite

Heart problems

☐ Change in weight

☐ Change in mood or depression

Lung problems

☐ Difficulties with breathing

☐ Memory or concentration loss

Low red blood cell count (anaemia)

☐ Low white blood cell count

☐ Infections

Pain or bleeding when urinating

☐ Urine incontinence

☐ Digestive problems

Menopausal problems

☐ Sexual problems

☐ Thromboembolic event

Fears and/or anxiety

☐ Other



Symptoms and side effects that have continued after finishing treatment:

Fatigue	<input type="checkbox"/>	Change in mood or depression	<input type="checkbox"/>	Pain or bleeding when urinating	<input type="checkbox"/>
Nausea and vomiting	<input type="checkbox"/>	Fears and/or anxiety	<input type="checkbox"/>	Urine incontinence	<input type="checkbox"/>
Pain and peripheral neuropathy	<input type="checkbox"/>	Lung problems	<input type="checkbox"/>	Digestive problems	<input type="checkbox"/>
Sleep disorders	<input type="checkbox"/>	Difficulties with breathing	<input type="checkbox"/>	Menopausal problems	<input type="checkbox"/>
Skin and soft tissue problems	<input type="checkbox"/>	Memory or concentration loss	<input type="checkbox"/>	Sexual problems	<input type="checkbox"/>
Loss of appetite	<input type="checkbox"/>	Low red blood cell count (anaemia)	<input type="checkbox"/>	Thromboembolic event	<input type="checkbox"/>
Heart problems	<input type="checkbox"/>	Low white blood cell count	<input type="checkbox"/>	Other	<input type="checkbox"/>
Change in weight	<input type="checkbox"/>	Infections	<input type="checkbox"/>		

Psychological and social aspects in survivorship

Psychological support:

☐ Family ☐ Friends ☐ Psychologist/psychiatrist ☐ Cancer support groups ☐ Social workers
☐ Health care professionals ☐ Other

Rehabilitation programme

YES NO

Rehabilitation programme	<input type="checkbox"/>	<input type="checkbox"/>
Psychological	<input type="checkbox"/>	<input type="checkbox"/>
Sexual	<input type="checkbox"/>	<input type="checkbox"/>
Cognitive	<input type="checkbox"/>	<input type="checkbox"/>
Nutritional	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>

Duration of rehabilitation programme:

Changes in family relationships:

Changes or difficulties by returning back to work:

Wish to extend family: ☐ YES ☐ NO

What concerns do you have as you begin your survivorship experience?

Emotional and psychological status	<input type="checkbox"/>
Cognitive problems	<input type="checkbox"/>
Weight changes	<input type="checkbox"/>
Fatigue	<input type="checkbox"/>
Self confidence	<input type="checkbox"/>
Life priorities	<input type="checkbox"/>
Body image	<input type="checkbox"/>
Physical strength	<input type="checkbox"/>
Going back to work	<input type="checkbox"/>
Financial advice	<input type="checkbox"/>
Parenting	<input type="checkbox"/>
Relationships issues	<input type="checkbox"/>
Sexual health and desire	<input type="checkbox"/>
Fertility	<input type="checkbox"/>
Stopping smoking	<input type="checkbox"/>
Pain	<input type="checkbox"/>
Other	<input type="checkbox"/>



Follow-up care plan

YES NO

Need for ongoing (adjuvant) treatment for cancer:

☐ ☐

End of main treatment:

Sign or symptoms to tell the doctor about right away:

SCHEDULE OF FOLLOW UP VISITS

Doctor's name	Time of visit

SURVEILLANCE CLINICAL EXAMINATION AND FOLLOW-UP IMAGING AND LABORATORY TESTS

PLAN:

Clinical exam/follow-up visit ☐ ☐ months

Radiologic examinations (specify) ☐ ☐ months

Blood tests months ☐ ☐ months

Endoscopy (specify) ☐ ☐ months

Other (specify):

Test/Examination	When	Results



Survivorship Guide & Care Plan: A powerful advocacy tool

- Offers evidence based, reliable survivorship information by the leading European medical oncology scientific organization and umbrella cancer patient organization
 - Offers a summary of family cancer history, cancer diagnosis, treatment, adverse events, follow-up care in one easy to consult form
 - Useful tool for all medical professionals that the patient/survivor may consult after end of treatment
 - Can be easily integrated to discharge instructions
-

Advocacy for the adoption of the Survivorship Care Plan in Greece

- Build strong collaborations with medical cancer societies – Seek their endorsement of the Guide
- Present how the Survivorship Care Plan will facilitate their work
- Make it widely known
- Convince health care system officials about the benefits of the plan

Advocacy Goal:
Make the Survivorship Care Plan
a mandatory integral part of the discharge instructions

Practical steps

- Translate the guide in your language
- Organize a press conference to present it
- Distribute widely to patients, hospitals, local press and key opinion leaders
- Meet hospital administrators, oncology dept. directors, health policy makers, Health Ministry to present the guide
- Use every opportunity to speak about it in conferences, tv shows, interviews, community events in which you are invited
- Use the power of social media to promote and make the guide known



Be persistent, Be patient, Use evidence

Be a Change Agent

- Don't get discouraged
- Results do take time to materialize
- Refine your tools and methods
- Build strong alliances around your goal

Ask for assistance

Keep us informed of your efforts



Thank you for your attention

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