



FEDERAZIONE
CURE
PALLIATIVE
ONLUS

REPORT DAL XVI CONGRESSO EAPC
BERLINO, 22-25 MAGGIO 2019
CHIARA CARAFFA
LUCA MORONI

EAPC 2019

16th World Congress of the European
Association for Palliative Care

Global palliative care – shaping the future

23 – 25 May 2019 | Berlin, Germany



22 maggio 2019

giorno precedente all'inaugurazione



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WORKSHOP: ENABLING LEADERS IN PALLIATIVE AND END OF LIFE CARE

Promosso da



Co-funded by the
Erasmus+ Programme
of the European Union

EDUPALL è un progetto finanziato dalla UE nell'ambito Erasmus finalizzato a sviluppare un piano di studi standardizzato per le cure palliative universitarie, diversificare l'insegnamento e valutare i metodi dei programmi educativi.

<http://www.professionalpalliativehub.com/education/edupall>

Da segnalare l'intervento di Eduardo Bruera, sempre brillante e di ispirazione per i giovani, e di Daniela Mosoiu, rinnovata come membro del Board di EAPC 2019 2023

Interessante l'utilizzo di APP che rendono possibile l'interazione in tempo reale della platea con i relatori, attraverso domande dalla sala, messaggi e questionari interattivi. Per visionare il programma completo del Congresso <https://www.eapcnet.eu/>

What happened between 2009 and 2018 ?

- Early (and late)palliative care improves patient's symptoms and quality of life (Anderson data)
- Early palliative care has positive or neutral survival effects (Anderson data)
- The name supportive care removes barriers to early referral (Anderson data)
- Palliative care improves NQF quality outcomes (Anderson data)
- Palliative care reduced the overall cost of care



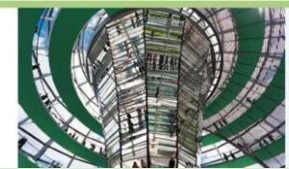
23 maggio 2019, apertura ufficiale dei lavori



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Alla **cerimonia di inaugurazione**
hanno partecipato
oltre 3.000 persone provenienti
da più di **100 Paesi del mondo**.



**Il Congresso Mondiale della EAPC ha dedicato
per la prima volta un seminario di una intera
giornata alle Cure Palliative Pediatriche:
Global challenges in Paediatric Palliative Care**



EAPC Award Presentation

La premiazione di Carlos Centeno da parte del presidente uscente di EAPC, Philip Larkin, è stata seguita con viva partecipazione.

Lukas Radbruch (Bonn, Germania)

ha presentato un resoconto su passato, presente e futuro delle cure palliative (*Global Palliative Care - Past, Present, Future*), a partire dalla recente definizione dell'IAHPC. Si tratta di una definizione discussa - esito del lavoro di delegati da 88 Paesi - che propone una visione molto ampia delle CP, ma che alcuni avrebbero voluto ancora più inclusiva.



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Palliative Care Definition IAHPC 2019

Component 1:
Palliative care is an approach that improves the quality of life of patients and their families...

	<input type="checkbox"/> still applicable	<input type="checkbox"/> needs to be revised	<input type="checkbox"/> do not know
Palliative care is the active, total care of patients with serious health-related suffering which aims to improve the quality of life of patients, their families and caregivers.			
1. Palliative care includes early identification, comprehensive assessment and adequate management of: - Pain and other distressing symptoms - Psychological distress - Spiritual distress - Social needs			
2. It endeavours to enhance the course of an illness, relative to the patient's need			

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life.

It aims to improve the quality of life of patients, their families and their caregivers.

IAHPC
<https://hospicecare.com>

<https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/>

Alleviating the Access Abyss
Lancet Report (2017)

Figure 3. Distribution of opioid consumption worldwide by region and population size, 2010-2015. Source: International Narcotics Control Board (INCB), 2016. See <https://www.incb.org/en/press-releases/2016/09/2016-09-01>

Knaut et al. Lancet 391(2018) 1391-1454

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Radbruch ha evidenziato l'enorme disparità nel consumo di oppioidi nei diversi continenti e la necessità di intervenire per ridurre le differenze nell'accesso ai farmaci.

Per visionare gli e-posters presentati ai lavori
<https://www.morressier.com/signup/EAPC-2019>

23 maggio 2019



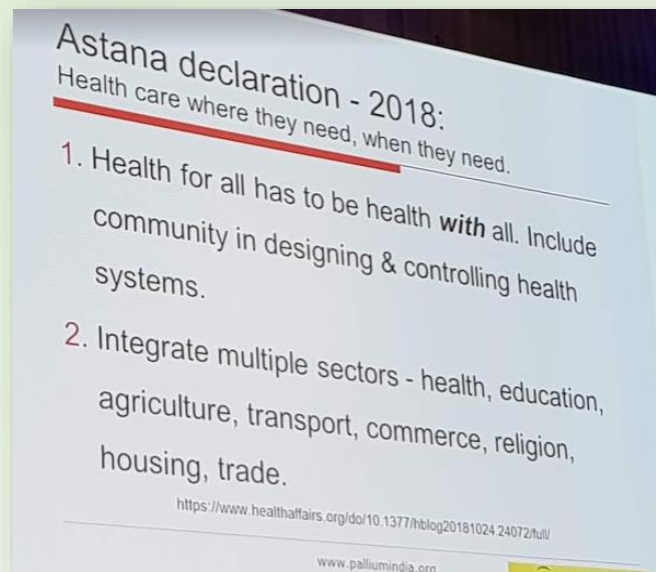
Illuminante l'intervento di **M.R. Rajagopal** (Trivandrum, India) Access to Palliative Care and Pain Relief - an Imperative of Universal Health Floriani Lecture



(...) **“Possiamo rompere il guscio?**
Non dovremmo essere intrappolati nella zona di comfort delle cure palliative di oggi. Possiamo essere agenti di cambiamento - portando l'assistenza ad una “nuova normalità” - vera cura della salute”.

Nel citare la dichiarazione di ASTANA 2018 .
Rajagopal sottolinea alcuni concetti cari a FCP:

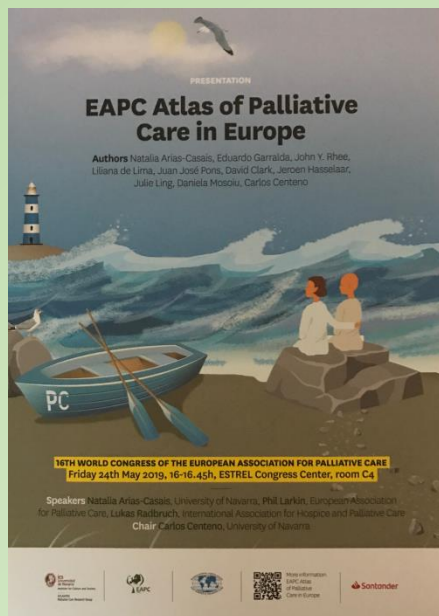
1. la salute per tutti deve essere salute **CON** tutti. Include le comunità nel disegnare e controllare i sistemi sanitari
2. Integrare molti settori: salute, educazione, agricoltura, trasporto, commercio, religione, housing, commercio



Da segnalare **due importanti pubblicazioni** presentate il 23 Maggio 2019



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Il Prof. Carlos Centeno ha presentato e illustrato la nuova edizione di **EAPC Atlas of Palliative Care in Europe** che contiene una interessante scheda relativa alla quantificazione del bisogno di CP per Paese e area di patologia

<https://eapcnet.wordpress.com/2019/05/24/new-edition-of-eapc-atlas-of-palliative-care-in-europe-launches-at-16th-eapc-world-congress-in-berlin/>

Mons. Paglia ha presentato il **White Book for Global Palliative Care Advocacy** redatto dalla **Pontificia Accademia per la Vita**. Il documento, esplicitamente finalizzato a promuovere attività di tutela dei diritti delle persone malate attraverso un processo di Advocacy, è rivolto ai differenti stakeholder: politici, università, ospedali, pazienti, associazioni, farmacisti, assistenti spirituali, mass media.



<https://www.ncbi.nlm.nih.gov/pubmed/30256135>

Alcuni spunti emersi dalle relazioni:

Appropriate methodology depends on availability of methodologists and clinical academics



There are more professors of oncology here...



...than professors of palliative care on the planet



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<https://eapcnet.wordpress.com/2017/06/14/equality-of-opportunity-in-academic-palliative-care-whats-the-problem/>



Ross Scott (UK) ha presentato la **Charter** sul Volontariato di EAPC, raccomandando di proseguire nella raccolta firme, promossa anche da Leena Pelttari in occasione del recente Convegno della FCP a Milano.



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Katherine Sleeman (UK)

Increasing the value of research in Palliative Care

Merryn Gott (New Zealand)

Esiste una medicina di genere nelle cure palliative:

le **donne** hanno maggiore carico assistenziale, minori probabilità di essere adeguatamente curate, minore caregiving.

Gli **uomini** hanno più probabilità di ricevere cure attive sproporzionate e forme di accanimento terapeutico

Is palliative care biased?

<https://eapcnet.wordpress.com/2019/05/17/is-palliative-care-biased/>



24 maggio 2019



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Il Presidente **Phill Larkin** ha incontrato i Presidenti o delegati delle **National Associations**

L'Italia è stata rappresentata da **SICP** e **FCP**



Achievements 2015-2019

- Greater governance and transparency.
- Clearer structures policies and procedures within the EAPC.
- Established relations with Council of Europe, WHO & Global partners
- Visible success of our Congresses - Dublin, Madrid and Bern
- Website updated and upgraded - a platform for dissemination
- Task forces and Reference groups growth and development
- Reflecting our diversity and inclusivity.

11th 

World Research Congress of the European Association for Palliative Care
13-16 May 2020 Palermo, Italy



ORGANIZING SECRETARIAT
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E-mail: congressi@bibigroup.it • www.bibigroup.it

www.eapc-2021.org

EAPC 2021

17th World Congress of the European Association for Palliative Care

Exploring new dimensions

20 – 22 May 2021
Helsinki, Finland

#EAPC2021



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE
www.eapcnet.eu



The Finnish Association for Palliative Medicine (SPLY)
www.palliativisenlaaketieteenyhdistys.fi



The Finnish Association for Palliative Care (SPHY)
www.sphy.fi

Sono stati formalmente annunciati i prossimi appuntamenti istituzionali: il Congresso **EAPC RESEARCH 2020**, che si svolgerà a **Palermo** dal 13 al 16 maggio 2020, e il XVII EAPC World Congress ospitato a Helsinki Nel 2021.

EAPC incoraggia i membri a unirsi alle attuali o ad avviare nuove Task Force

EAPC 2019 16 th World Congress of the European Association for Palliative Care Global palliative care – shaping the future 23 – 25 May 2019 Berlin, Germany	
Friday, 24 May 2019 Room 4 (2 nd floor)	Friday, 24 May 2019 Room 5 (2 nd floor)
08:00 – 08:45 Open Meeting of the EAPC Reference Group on Intellectual Disabilities	07:00 – 08:00 Closed Meeting of the new EAPC Task Force on Advance Care Planning with Dementia
10:30 – 11:15 Open Meeting of the EAPC Taskforce on International Collaboration on Guideline Development	08:00 – 08:45 Closed Meeting of the EAPC Task Force Last Aid
12:55 – 14:15 Open Meeting of the EAPC Primary Care Reference Group	10:30 – 11:15 Open Meeting – New EU-funded Palliative Care Research: an Overview of All Projects Launching 2019
Friday, 24 May 2019 Room 4 (2 nd floor)	EAPC 2019 16 th World Congress of the European Association for Palliative Care Global palliative care – shaping the future 23 – 25 May 2019 Berlin, Germany
16:00 – 16:45 Open Meeting of the EAPC Taskforce on Preparation for Practice in Palliative Care Nursing across the EU	Friday, 24 May 2019 Room 5 (2 nd floor)
18:30 – 19:45 Open Meeting of the EAPC Task Force Mapping Palliative Care Provision for Prisoners in Europe	12:55 – 14:15 Open Meeting of the EAPC Task Force on Volunteering in Hospice and Palliative Care
	14:30 – 16:00 Open Meeting of the EAPC Task Force Medical Education
	16:00 – 16:45 Closed Meeting of the EAPC Task Force on Heart Disease
	EAPC 2019 16 th World Congress of the European Association for Palliative Care Global palliative care – shaping the future 23 – 25 May 2019 Berlin, Germany
	Friday, 24 May 2019 Room 5 (2 nd floor)
	18:30 – 19:45 Open Meeting of the EAPC Task Force on “Big Data in End-of-Life Care Research”



FCP ha partecipato alla elezione del nuovo Board di EAPC:

Il prof. Christoph Ostgathe è il nuovo Presidente.

La d.ssa Danila Vanenti è stata confermata come membro del Board.

Maggiori informazioni <https://www.eapcnet.eu/about-us/eapc-board-2019>

25 maggio 2019



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La **EAPC** ha creato una serie di Task Forces a supporto della analisi dei problemi e del raggiungimento di obiettivi tangibili.

Lo Steering Committee della Task Force sul Volontariato ha fortemente voluto che **FCP** entresse a farne parte, invitando un Consigliere a rappresentare la realtà italiana al Simposio *Volunteers at the heart of Hospice and Palliative Care.*

Bereavement	Children & Young People	End of Life Care Research Big Data
Health Care Guidelines	Heart Disease	Last Aid
Medical Education	Nurse Education	Prisoners
Refugees and Migrants	Social Work	Spiritual Care



Date Sat, 25th May 2019
Time 10.00 am – 5.00 pm
Location ESTREL Congress Center
Sonnenallee 225
12057 Berlin
Germany

Please sign up for the Symposium here:
<https://eapc2019.eventbrite.net>
no registration fee



We are grateful for the support of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, Germany, and the support of ERSTE Foundation for funding travel costs for participants from Eastern European Countries.

Please contact: anna.pissarek@hospiz.at
<https://www.estrel.com/en/locations-directions.html>



Programme



Sat, 25th May 2019 | 10.00 am – 5.00 pm
Estrel Congress Center, Berlin

**INTERNATIONAL SYMPOSIUM
"VOLUNTEERS AT THE HEART OF
HOSPICE AND PALLIATIVE CARE"**
Opportunities and Challenges 2030

Simultaneous Translation
English / German

Free admission

Sponsors:
1 EAPC Task Force on Volunteering in Hospice and Palliative Care in Europe
2 German Association for Palliative Medicine
3 German Hospice and Palliative Care Association
4 Hospice Austria

Funded by:
Federal Ministry for Family Affairs, Senior Citizens, Women and Youth

International speakers

 <p>Dr. Franckla Gilley Federal Minister for Family Affairs, Senior Citizens, Women and Youth, Germany Petron</p>	 <p>Prof. Dr. Christoph Orthogier EAPC Vice-President (2016-2019), Professor of Palliative Medicine and Head of Department of Palliative Medicine at University of Vienna, Germany</p>	 <p>Prof. Dr. Lukas Balduwisch President of the German Association for Palliative Medicine, Member of the Steering Group EAPC Task Force on Volunteering in Hospice and Palliative Care in Europe</p>	 <p>Waldemar Klancic President of Hospice Austria</p>	 <p>Dr. Ina Anja Schneider Vice-President of the German Hospice and Palliative Care Association, PhD in Care Management, CEO of Anhaltische Hospiz und Palliativgenetischhaft.</p>	 <p>Fatia Kiyang, MA Programmes Director at the African Palliative Care Association (APCA) since 2005. She has worked in the area of palliative care and health for 18 years. Her role at APCA focuses on palliative care advocacy, policy development and implementation, education and training and programme design and management. She was awarded the third highest civilian honour, "Paloma Dini" by Government of India in 2018. She is one among 50 most influential volunteers in palliative care by American Academy of Hospice and Palliative Medicine (AAHPM) in 2015.</p>	 <p>Dr. Ben Scott Researcher and consultant in the field of volunteering, honorary research fellow at the University of Dundee. Co-Chair of the EAPC Task Force on Volunteering in Hospice and Palliative Care, Vice-Chair of Civic Bereavement Care Scotland, a member of the Scottish Advisory Board for Hospice Care.</p>	 <p>Mag. Leona Pettrari CEO of Hospice Austria, Co-Chair of Hospice and Palliative Care in Europe, Chair of the EAPC Task Force on Volunteering in Hospice and Palliative Care in Europe, Chair of the EAPC Task Force on Hospice and Palliative Care in Europe.</p>	 <p>Dr. Karl Bittschau Vice president of Hospice Austria, Head Hospice Österreich</p>	 <p>Chloé F. R. Carolla Member of the board of the Palliative Care Federation (PCF Italy) General Manager of Prosema Amica, a non-profit organization that deals with coordination for volunteers at the end of life and accompaniment of the end of life and volunteer programs in the hospice and palliative care internationally.</p>	 <p>Prof. Dr. Anne Gassenman Professor at University of Humanistic Studies in the Netherlands on research into self-care and volunteering in hospice and palliative care. She coordinates a pre-master course 'Spiritual care at the end of life' at the University of Groningen and provides lectures about care relationships and theory of personhood, specializing in medical law, hospice and palliative care and volunteering. Enriched with non-governmental organizations, the Hospice Foundation, the Rother E. Durlacher (DE) Hospice in Cologne and the Polish Psycho-Oncology Association.</p>	 <p>Steven Vandendriessche Sociologist and doctoral researcher in the field of Life Care Research Group of the Vrije Universiteit Brussel and Ghent University (Belgium). He was a member of the INTCARE project, working in palliative care. He is currently a member of the EAPC Task Force on Volunteering in Hospice and Palliative Care. He is teaching health care workers and volunteers.</p>	 <p>Dr. Agnes Zanz Board member of the Hungarian Hospice Association, Hospice Austria, Hospice Österreich. She is teaching health care workers and volunteers.</p>	 <p>Dr. Celia Beigada Researcher at ATLANTIS-Human Dignity, Advanced Ethics and Palliative Care of the Institute for Culture and Society, University of Navarra (Spain), Co-Chair in Palliative Care and PhD in Psychology. Board Member of the Portuguese Palliative Care Commission (Ministry of Health - Government of Portugal), and Portuguese representative of the EAPC Social Work Institute.</p>	 <p>Leszek Pawlowski PhD. Lecturer who joined the Department of Palliative Medicine, Medical University of Gdansk in 2002. He is currently an assistant professor, specializing in medical law, hospice and palliative care and volunteering. Enriched with non-governmental organizations, the Hospice Foundation, the Rother E. Durlacher (DE) Hospice in Cologne and the Polish Psycho-Oncology Association.</p>
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Looking forward to interesting lectures and intensive discussions

Lo scopo della Task Force **EAPC** sul volontariato, di cui fanno parte 49 membri provenienti da 15 Paesi è quello di **promuovere e potenziare il volontariato HPC in Europa**.
La sintesi del nostro lavoro è stata presentata al Simposio al cospetto di oltre 300 ospiti, tra cui il Professor M.R. Rajagopal – Pallium India.



Development and current state of Volunteering in hospice and palliative care in Italy

The Federation of Palliative Care



The Federation of Palliative Care (FCP) is a second-level organization of the Italian third sector that represents the network of Non-Profit Organizations (NPOs) operating in the field of palliative care of the country. 50 Non-Profit Organizations are currently members of the FCP gathering more than 4,000 Volunteers.

The FCP, active in helping and assisting people with an evolutionary and incurable disease with poor prognosis, was established in 1999 with the aim of promoting and developing palliative care, operating to culture and preserving dignity of the person, also guaranteeing the right not to suffer.

The Federation of Palliative Care (FCP) is in constant relationship with the NPOs associated and maintains ongoing close working relationships both with the Italian Society of Palliative Care (SICPA) and with a significant number of external NPOs.



Law February 26th 1999, No. 39
"Provisions to ensure urgent action to implement the 1998-2000 National Health Plan"

The Minister of Health [...] adopts a program on a national basis for the realization, in each autonomous region and province in consistency with the objectives of the National Health Plan, of one or more structures, located in the territory in order to allow easy accessibility for patients and their families, dedicated to palliative care and to care primarily for patients affected from terminal neoplastic disease requiring care aimed at ensuring a better quality of their life and that of their families.

Law March 15th 2010, No. 38
"Provisions to guarantee access to palliative care and pain therapy"

L.1 Having heard the main scientific societies and non-profit organizations operating in the palliative care and pain therapy sector, homogeneous training courses are diffused throughout the national territory for the volunteers who work in the two networks (Federation of Palliative Care - FCP and Italian Society of Palliative Care - SICPA).

Law December 22nd 2017, No. 219
"Rules on informed consent and Advance Health Care Directive"

The time of communication between doctor and patient constitutes care time.



FCP increase its coordinators year by year



95% of FCP members has Volunteers



Our concrete response: evolution in collaboration with the Italian Society of Palliative Care

The role of the Volunteer in Palliative Care
The presence of volunteers allows the sick person to remain in their home, to be cared for in a familiar environment, to be accompanied by their family and to be cared for in a familiar environment.

VOLUNTEERS BRING THEIR PRESENCE
This happens in a context in which being there is a preliminary, the volunteers are present where suffering, loss of autonomy, health prognosis lead to risk of institutionalization and isolation.

VOLUNTEERS ARE FACILITATORS OF THE RELATIONAL WORLD OF THE SICK
Volunteers offer an emotional support, for relationship and closeness especially in moments of profound loneliness. Due to the global nature of the disease facing to emotional relationships, sick people are helped to be in great difficulty even when having a family, friends and acquaintances. They attempt to maintain a relationship capable of giving assistance and response to the needs of

relationship, closeness, care. Prepared volunteering does not replace itself but helps the family to play a fundamental role.

VOLUNTEERS ALLOW MOMENTS OF NORMALITY
The presence of volunteers allows the sick person to remain in their home, to be cared for in a familiar environment, to be accompanied by their family and to be cared for in a familiar environment.

VOLUNTEERS OFFER SUPPORT AND EMOTIONAL SHARING IN RELATION TO UNDESIRABLE DISEASE
A prepared volunteer knows how to "stay" in a conversation even when it concerns illness, death, suffering, concerns for the future of the sick or of family members.

Although aware of not having solutions or answers, the volunteers can create a positive environment through listening, understanding and through emotional participation for the family of people in whom he has truly chosen to dedicate time.

VOLUNTEERS PERFORM A SOCIAL ROLE
The volunteers, together with the associations, represent a member of the community capable of bringing the outside world to places of care, overcoming physical barriers, limited in helping or, in any case, verbal, mobility. In the same way, the Association, through the volunteers, can transfer information sensitivity, values such as transparency, mutual aid, experience, listening to group, solidarity, that can give support, capable of expressing closeness and inclusion that is lack people.

The Federation has always been committed to collecting data related to the associated NPOs and to all those active on the national territory, with the purpose of providing the citizens who needs care or information direct contacts with the organization operating in their geographical area.

The Federation has collected the data of the associated NPOs in 2012 (69 NPOs), in 2013 (75 NPOs) and it is currently processing the recently acquired data about 91 NPOs, not yet available.



95% of FCP members has Volunteers

The publications of the Palliative Care Federation best practices made through heterogeneous working groups

Since 2008, the FCP has published the "Piano e Virgola", which meaning is unit-culture, review, the result of the experience of the members of the coordinate organizations and of the most authoritative Italian voices in the field of palliative care. The volumes intend to welcome and guide the NPOs and the assisting Volunteers, accompanying them in their path, they offer Food for thought and relevant information to the citizens, support the work of the professional caregiver teams.

Needs of Palliative Care in Italy. An FCP-SICPA document Italian population - 60 million 494 thousand residents in 2017. Approximately 80,000 people died in Italy.

Needs of Palliative Care
Prevalence: 1:14 of the adult population Estimate: between 284.000 and 738.000 people
Incidence: 721-801 compared to the number of deaths / year Estimate: 465.000 - 1.37.600 people every year

Palliative Care Report on implementation status of law No. 38/2010, three-year period 2013-2017
Language
No. of admissions: 42.272
71,5% of the total cancer patients
Hosp. No. of assisted patients - 40.849



95% of FCP members has Volunteers

CHALLENGES Board of Directors FCP 2018 – 2022

MAPPING
It is necessary to collect, through an accurate survey, data and information both on the organizations that provide Palliative Care services and pure voluntary organizations, in quantitative and qualitative terms, with the aim of having an overview of the current scenario and conducting an analysis on possible improvement paths.

NON - ONCOLOGICAL PATIENTS
We want to guarantee access to palliative care for non-cancer patients by implementing care pathways, consistent with the needs, timing and specific characteristics that characterize the assistance of the different categories of patients.

SHARED CARE
We know that end-of-life care is not enough. Timely and early management procedures have to be promoted. These are characterized by interventions by caregivers with the health specialist, aimed at the management and shared planning of care with the patient.

TRAINING / INNOVATION
Specific training projects, aimed at implementing integrated palliative care pathways, for specialist teams, GPs, PHNs and hospital health workers, nursing homes / Residents for Disabled and Integrated Home Care, have to be developed. The Federation intends to develop, in synergy with voluntary organizations, information and awareness projects aimed at citizens.

INSTITUTIONAL ACCREDITATION
The relationship of NPOs with the National Health System and Regional Health Systems must be regulated exclusively through "Institutional Accreditation". All conventional forms must therefore be reviewed, in particular the allocation of services (ambulatory and hospital). The management of the Accredited Structures (Hospital and Domestic UCPI) cannot be outsourced, by the Accredited Body, through "calls for tenders".

La Task Force **EAPC** sul volontariato è impegnata nella realizzazione di una serie di progetti, tra i quali l'organizzazione futura di altri Simposi internazionali che seguano l'impronta di quelli tenutisi a Praga, Vienna e Berlino, la stesura dell'Atlante sul Volontariato e del White Paper della EAPC, la diffusione della Carta dell'EAPC di Madrid.



La **Carta di Madrid**, incentrata sul volontariato e tradotta in 12 lingue, persegue tre obiettivi principali:

- Incentivare lo sviluppo positivo del volontariato a beneficio delle persone malate, delle loro famiglie e della più ampia comunità
- Riconoscere il volontariato come terza risorsa - accanto all'assistenza professionale e all'assistenza familiare - di cui siano chiare l'identità, la posizione e il valore.
- Promuovere modelli di ricerca e migliori pratiche nel reclutamento, gestione, supporto, integrazione, formazione e risorse dei volontari.

<http://bit.ly/EAPCVolunteeringCharter>