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MESSAGE FROM THE SECRETARY

Dear Friends,

We are back from the Central Council Meeting of IAPC at Bangalore. We had a full day to discuss and plan the activities of IAPC. One of the agenda was reviewing the Strategic Plan that we made in 2005. Some of the short term objectives were achieved and many are partly achieved or still to achieve. The broad goals for 2010 were

50% of the population to be aware of palliative care

20% of those in need to be receiving palliative care services

75% of states to be making morphine readily available to patients

50% of the IAPC membership to be nurses, social care staff, volunteers and others

All these are grossly under achieved.

Except for some places where there is 'hyper activity' the palliative care development in the country has been slow. Our national coverage is still grossly inadequate. You can see the early results of a nation wide survey of existing palliative care services in this newsletter. I am not trying to paint a gloomy picture of palliative care scene in India. This is just to remind ourselves that we have "miles to go". Though IAPC is sixteen years of age, I would say we are still pioneers because there still remains so much for us to achieve. And as pioneers we have to do justice to our selves and the generations to come by helping to develop sustainable and affordable palliative care programmes.

Our present work has given us so much credibility and social standing. How much have we been successful to take advantage of this situation to promote and influence

development of palliative care out side our institution or place of work? As pioneers we need to introspect.

It is high time that palliative care come out of the shell of charity. It should be a right of every one, not just some thing for which people have to beg. Palliative care, if we look at its basic principles, can be seen as a part of the larger picture of "dignity of life" which is a right of every person.

Another World Hospice and Palliative Care Day is approaching. What are we going to do on that day? Let us, as pioneers, take this opportunity to introspect, to take stock of the situation and to plan the future activities to take palliative care to those who need it and which is their right as well.

And please do share your thoughts, plans and actions with us.

Warm regards

Anil

CONFERENCE INFORMATION

IAPC Conference 2010

17th International conference of IAPC

Venue : Thiruchirappally (Trichi), Tamil Nadu

Date: 12th to 14th February-2010

The objective of the conference is to update the palliative care today and to have a vision for tomorrow. The theme is "light up the twilight years" necessitating "Bringing the excellence for the elderly".

Register Now

For other details and registration please contact the organising secretary of the conference,

Dr. T. Mohanasundaram, Sudharsana Palliative Care Hospital, 119-D, Palayam Bazar, Woraiur, Thiruchirappally Tamil Nadu, India: 0431-2761171.

log on to www.palcontrichi.com or

Email to mohan.sudharsana@gmail.com

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CHANDIGARH PALLIATIVE CARE SERVICE



Chandigarh Hospice

The Chandigarh Palliative Care Service was started with the aim of 'Integrating Palliative Care into Comprehensive Cancer Care' and providing 'Continuity in Care' to the cancer patients. It is a joint project of the Department of Radiotherapy, Post Graduate Institute of Medical Education & Research (Government Institute) and the Chandigarh Branch of the Indian Red Cross Society (NGO).

The project started in 1998 as a Palliative Care Clinic in the Radiotherapy Department. Initially it functioned twice a week but now runs six days a week. The palliative care team shares the same outpatient department and the case records of the Radiotherapy and Oncology Department. The patients are familiar with the palliative care team even when they are on anti-cancer treatment. If the patient is in a stage to need more attention by the palliative care team they will be transferred to the Palliative Care Clinic and patients see it as a continuation of their care. This interaction between the Oncologist and Palliative Care Physician helps the patient as they can get cancer treatment and palliative care simultaneously throughout the trajectory of their illness.

Home Care

It has been realised in the mean time that for the continuation of palliative care the service should be extended to the patient's home. This became a reality when the Chandigarh Red Cross joined the project in 2000. The Home Care Service was started in Chandigarh and the neighbouring towns of Mohali and Panchkula.

The first home visit is always by the team of Doctor, Nurse, and Social Worker. After this, any of the team member visits the patient as per the patient's requirements. Seeing the patient in the home environment gives the team an insight into their family problems that cannot be imagined when the patient is seen as an individual in the Hospital. Lack of finances and facilities is the major problem in their houses.

So the Palliative care team started procuring gadgets like back-rests, commodes, walkers, wheel chairs, and hospital beds which are loaned out to the family, which they can later return.

There are no fixed intervals between home visits. Patients are seen either weekly or even on daily basis if required. Thus it has been possible to keep majority of the patients comfortable at home till the end. The team provides care not only to the patient but the whole family and 'Bereavement Support' is an integral part of the service.

Inpatient Unit

Patients who cannot be managed at home and the large number of patients who come to the institute from far off places for their symptom management needs institutional care. For meeting this need the hospice facility was started in a newly constructed dispensary building which was allotted by the then administrator of Chandigarh Lt.Gen.J.F.R Jacob. The hospice was inaugurated on 14th January 2003 with 10 beds and the bed strength has now been increased to 20. The service is completely free.

One of the aims of the service providers is to empower the relatives of the patient. So it has been insisted that a relative should stay with the patient so that they can be taught nursing care and how to manage the nutrition of the patient with simple household items.

Homely Atmosphere

In order to create a homely atmosphere all festivals are celebrated in the Hospice. Small family get-together and celebrations of patient's birthdays, anniversaries are also organized. Group activities are held twice a week and on the other days relaxation and breathing exercises are arranged in groups for the patients and relatives.



Cultural Programme

Community Participation

When the Hospice was started it was decided to involve the community to support this project. The community participation has been very encouraging. All the furniture, appliances and the things for daily need were donated. The drugs for the patients and ration for the kitchen are also regularly donated by individuals and organisations. People who have benefited from the hospice are coming back as volunteers and giving their time and helping other families cope.

Thus the hospice has been successful in Integrating Palliative Care into comprehensive cancer care which is of great benefit to the patient and family. The team also realised from their

experience that Government Institutions and NGO's can work together without duplicating facilities and the community participation in such projects is very essential and helpful. Chandigarh Palliative Care Service is now in the process of extending service to non cancer patients also.

For more information please contact:

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MEDIA WORKSHOP



Ms. Ammu Joseph addressing the delegates

A workshop on media relationship was organised by the Indian Association of Palliative Care on 22nd August 2009 at Karunashraya, Bangalore.

Ms. Ammu Joseph an independent journalist and author based in Bangalore, was the key note speaker. The topic was "Public Health Coverage and Media". Mr. KPM Basheer, Special correspondent, "The Hindu" lead an interactive session on "How to make media your Partner". He explained the practical aspects to be followed to make media a friendly partner.

Mr. Mahesh Guptan, Reporter, Malayala Manorama and Ms. Nisha, National Information Officer for palliative care presented a paper on the media campaign on palliative care in Kerala organised jointly by Institute of Palliative Medicine and the Malayala Manorama in 2008.

Twenty five delegates from different parts of India participated in the workshop. The workshop was supported by an advocacy grant from the Help the Hospices, UK.

NATIONAL FACULTY WORKSHOP

The Indian Association of Palliative Care is organising a two day workshop for national faculty members on 31st October and 1st November 2009 at Karunashraya, Bangalore. The topic of the workshop is 'End of Life Care'

The National Faculty Pool has been expanded with four new members. Now there are 67 members in the National faculty pool.

IAPC CERTIFICATE COURSE - APPLY NOW



Dist. Collector of Ernakulam Ms. Dr. M. Beena distributing certificate to candidate successfully completed the IAPC course from the regional centre at General Hospital Ernakulam.

The next batch of the IAPC Basic Certificate Course in Essentials of Palliative Care for doctors and Nurses will begin on 1st November 2009. Application forms are available from IAPC website www.palliativecare.in and also from the regional centres.

This is offered as distance education course with a 15 hours of mandatory contact session. The course fee is Rupees 1000.

For details contact nio.palliative.india@gmail.com

BRUCE DAVIS GOLD MEDAL 2009

National Level Exam in Palliative Medicine for Young Indian Doctors

For details visit: <http://bdgm.blogspot.com/>

Institute of Palliative Medicine, Medical College, Kozhikode, Kerala is conducting the national level examination for Bruce Davis Gold Medal in Palliative Medicine for young doctors in India.

Doctors who appear(ed) for their final MBBS examination between 31 December 2006 and 31 December 2010 from any Medical College in India can apply for the examination.

There will be two levels of examinations: an open screening test, comprising of 100 MCQs, at national level at the candidate's place and a final examination in Kozhikode.

There is no registration fee. The application form and questionnaire for the screening test are available from the blog <http://bdgm.blogspot.com/> These can also be collected from the nearby palliative care centres or Principals of many of the medical colleges. Candidates can work on the questionnaire on their own. A list of possible resources including books and web sites are enclosed. Guidance may also be available from the nearby palliative care units/specialists. The completed questionnaires along with the application forms should reach the Institute of Palliative Medicine, Pain and Palliative Care Society, WHO Demonstration Project, Medical College, Kozhikode- 673008, Kerala, India only by post before 15th November 2009. Ten top scorers in the screening test will qualify for the final examination to be held at the Institute of Palliative Medicine, Kozhikode.

The winner of the final examination will be awarded the Bruce Davis Gold Medal in Palliative Medicine, a citation and cash award of Rs. 25,000/- (Rupees twenty five thousand only).

100 LOCAL SELF GOVERNMENT INSTITUTIONS START PALLIATIVE CARE

The Arogya Keralam Palliative care Project implemented by the National Rural Health Mission in Kerala has shown good results in first year. One hundred Local self Governments in Kerala initiated Palliative Care Services with the help of the project and about 27,000 bedridden and incurably ill patients are estimated to have benefited. The project has been extended to second phase from 1st September 2009.

Kerala is the only one state in India where National Rural Health Mission is implementing a project in Palliative Care. Institute of Palliative Medicine, Kozhikode is the nodal agency.

The project in the first year was officially launched in October 9th 2008 in Kerala and the main objective is developing services for the bed ridden and incurably ill patients in the state in line with the Palliative Care Policy by the Government of Kerala. The project aims at awareness and capacity building in the general community, health care professionals in government and private sector, local self government officials and grass root level political leaders.

The Arogyakeralam project tried to develop a model system of delivery of Long Term Care and Palliative Care in the state with active collaboration from the community groups already working in the field, government hospitals, local self governments and also the private sector in health care. For this the first step taken was training Medical Professionals, Volunteers and others like ASHA workers, Social groups, Local Self Government Institutions (LSGI) members and students. Two thousand two hundred and twenty six



Inaugural function of the training program for doctors under Arogyakeralam Project at Trissur

awareness and training programmes were organised and more than one lakh people from different categories participated in these programmes in the first year.

All these people has been linked together regionally and provided a platform for working together. Trained groups and individuals have been linked with Initiatives in long term care and Palliative care in that region. Arogyakeralam project also provided all support to developing existing services in different regions where they are under developed.

Thirteen training centres have been developed in the state which offers Basic Certificate Course in Palliative Medicine (BCCPM) for doctors, Basic Certificate Course in Palliative Nursing (BCCPN) for Nurses and three month basic certificate course in Palliative Auxiliary nursing (BCCPAN).

NARCOTIC RULE AMENDED IN ANDHRA PRADESH

All palliative care centres in Andhra Pradesh will get the required amount of morphine without the complicated licensing process as the narcotic rules have been amended in the state. Thus Andhra Pradesh becomes the 14th state in India to amend and simplify its narcotic regulations in August 2009.

This is the consequence of about 10 years of effort. Following the Government of India order in 1998 to all states to amend their narcotic regulations, the Indian Association of Palliative Care (IAPC) and the Pain and Policy Studies Group had worked together to effect the change in Andhra Pradesh, but despite two workshops with Government officials and professionals, it had not materialised.

Following the establishment of a palliative care training centre at MNJ Institute of Oncology (MNJIO) as a joint initiative of MNJIO, International Network for Cancer Treatment and Research (INCTR), Pallium India, and American Cancer Society, the MNJIO team made renewed efforts. The public interest litigation filed by the Indian Association of Palliative Care to the Supreme Court of India gave added strength to these efforts.

Now the challenge is to improve and sustain the demand by the professionals and the community for morphine and ensure its proper use and accounting. It will require aggressive advocacy, training and education. The Ministry of Health and Family Welfare, the Medical Council of India, State Directorates of Medical Education, representatives of medical colleges, and palliative care providers should jointly

SCHOOL BASED AWARENESS PROGRAMMES



Puppet show for children

Awareness programme about childhood cancer has been launched in schools in Kozhikode district of Kerala by the organisation Caring for Children with Cancer and Chronic Illness (C4CCCI).

A puppet show with the message "childhood cancer is curable" has been organised as part of the programme. The result was positive. Toys and collection of coins were donated by students to console and help the suffering children afflicted with cancer.

Presentation regarding ongoing project and future objectives was organised at schools for teachers, members of the school management, and parents. Health awareness classes were also held.

develop a plan of action for this. It has been suggested to integrate palliative care into the primary care system of health as has happened in the state of Kerala to improve the access to care.

DEPARTMENT FOR PALLIATIVE MEDICINE AT KIDWAI MEMORIAL INSTITUTE OF ONCOLOGY, BANGALORE

Kidwai Memorial Institute of Oncology has been having palliative care services for more than a decade. In fact the pain clinic at the institute was one of the first such clinics in the country. Earlier it was under the department of anaesthesiology. In May 2009 the institute has set up a separate department for Palliative Medicine. This new department has out patient clinic, inpatient care, day care support and home based care with the help of hospital palliative care team. 'Day Care' programme for the cancer afflicted is on since June 2009 with the involvement of the team members of Department of Palliative Medicine and the volunteers from the 'Banjara Academy'. This has become a good opportunity for social interaction and sharing of experiences for many people living with advance illnesses. The team is also planning to organise social events for the group.



Planting a Honge plant in the Infosys block of KMIO

For more information please contact

Department of Palliative Medicine at 9972297459 or 080-26094100 or email to dpmkidwai@gmail.com

DNip CARE EXTENDS ITS ACTIVITY

Delhi's National Initiative in Palliative Care (DNip Care), the community based palliative care group started in the bustling metropolis of Delhi, a year ago, has now been extended its activity to the adjacent National Capital Regions like NOIDA, Ghaziabad, Gurgaon and Faridabad with the active support of other local socio cultural and community organisations. Now DNip Care has a volunteer base of more than 50 in New Delhi itself with people from different fields like government service, private sector, business establishments and medical and paramedical professions. Coming together from all walks of life, they regularly follow up patients from all parts of Delhi.

The patients and volunteers hail from various states of India come together under the DNipCare umbrella shows that



Get together of volunteers

the humanity transcends borders and differences. Patients having cancer, paraplegia, thalassemia, muscular dystrophy as well as bedridden from accidents were benefited by the service.

DNip Care focuses mainly on providing psycho-social support to the patients and their families. The volunteers visit patients at their homes on a regular basis. On an average there will be two per patient. Monthly food kits and medicines are also being provided to some of the patients who need such support. Logistical support to the patients for availing Governmental and non-governmental assistance is also given by the organisation.

The monthly review and planning meetings, being held on the second Saturday of every month at Kerala Club, Delhi, is a forum for brainstorming on medico-social issues that the patients face in the course of their treatment. Experts from the medical field participate in the discussions.

DNipCare has an expert group of doctors providing medical advices and home care. They include Dr. Susheela Kutty, Dr. Sarah Walter, Dr. Koshi Cherian, Dr. Grace Cherian, Dr. Suresh Mohammed, Dr. Sindhu Sunil, Dr. D.P Singh and Dr. Nishad.

For more information please contact

K.V. Hamza (mob: 09891008356)

or P.P. Abdul Khalik (mob: 09990227777)

or mail to dnipcare@rediffmail.com

INTERNATIONAL PALLIATIVE CARE NETWORK POSTER EXHIBITION 2009

To commemorate its second anniversary, the Palliative Care Network has announced an online poster exhibition, to be hosted by the Palliative Care Network Community. Participation is free and is open to all palliative care professionals from across the globe. The top poster will receive a prize of \$500 (US dollars). There will also be prizes for second and third placed posters.

The deadline for submissions is
15 October 2009.

For more details Email to
posters2009@palliativecarenetwork.com

Or search

www.pcn-e.com/community/pg/profile/posters2009

GET TOGETHER OF CANCER PATIENTS

A get together of cancer survivors, suffering patients, their relatives and staff members was organised at the Jawaharlal Nehru Cancer Hospital and Research Centre, Bhopal on 31 July 2009 with a view to boost the morale of the cancer patients undergoing treatment and the programme is part of the hospital's initiatives to strengthen the palliative care activities. Nearly 60 cancer survivors participated. Mr. Madan Mohan Joshi, Chairman of Jawaharlal Nehru Cancer Hospital & Research Centre announced that the hospital has planned such interactions between the survivors and patients on regular basis.

NEWS FROM THE EDITOR **INDIAN JOURNAL OF PALLIATIVE CARE**

IJPC is the only Journal in Palliative Care regularly published from developing countries.

The editorial board of the Journal is now based at New Delhi and the Chief Editor is Dr. Sushma Bhatnagar, Associate Professor & Head, Unit of Anesthesiology, Dr. B.R A Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi - 110 029, India.

It is a well known fact that there are barriers and difficulties to conduct research in the area of palliative care due to reservation and concerns about ethics and clinical trials on patients nearing their end of life. This constraint makes research in this niche area more challenging and despite all reservations it is highly desirable to contribute authentic evidence based treatment developments to the scientific knowledge pool. Among others, evidence based symptom palliation and evolving psychological support mechanism is one of the most important areas in delivering high quality palliative care.



Editorial team wish to make this journal one of the most comprehensive, versatile and a must read by all in future. This demands high quality original articles from all young scientists, nurses, social workers, psychologists, clinicians and care givers in this noble area of palliative care. Dr. Sushma Bhatnagar request all the readers of this news letter to send good quality articles for this journal.

The cover page and contents have gone a subtle change from June issue and editorial team wish to work for further improving the quality. June issue onwards this journal is fully online including submission, review, review corrections etc.

Eventually, editorial team wish the number of issues to increase from biennial to quarterly depending on the popularity and increased awareness of palliative care in the developing world countries.

For getting the Journal online Search: <http://www.jpalliativecare.com>

PRELIMINARY REPORT FROM THE SURVEY OF PALLIATIVE CARE SERVICES IN INDIA

IAPC has done a survey of the palliative care services in India to make an online directory. For this a questionnaire has been circulated among all known palliative care services in India and we have received 238 responses.

We are sure that it may not be covering all the palliative care service providers in India but gives a general idea of the services available in the country.

Following is a brief report on the data collected.

Number of centres in different states.

State	No.of known Palliative Care Providers
Andra Pradesh	4
Assam	3
Chandigad	1
Delhi	4
Jharkhand	1
Karnataka	7
Kerala	193
Maharashtra	3
Madya Pradesh	2
Punjab	1
Rajasthan	2
Tamil Nadu	13
Uttarpradesh	2
West Bengal	2
Total	238

Basic service provided by these centres

▶ Centres providing only OPD Care	191
▶ Centres providing only Inpatient care	69
▶ Centres providing Home Care Service	209
▶ Centres providing Palliative Care for Children	125
▶ Centres providing Palliative care to non Cancer patients also	160
▶ Centres requiring referrals for treatment	66
▶ Centres providing care free of cost to all patients	192
▶ Centres providing all these services	12

These are only basic details involved in the questionnaire. Detailed report regarding all centres will be published in the coming issues. There has been a recent surge in the development of new services in Kerala in the last couple of years following the involvement of Local Self Government Initiative and planned

support from the National Rural Health Mission. This will explain the large number of services in the state.

We know that this directory is an evolving one and there may be palliative care providers in India other than these. But we don't have any information regarding those centres at the moment. We are hopeful of collecting the data on all the centres in near future.

The questionnaire is available from the website. Any palliative care services who have not received the questionnaire can download this from the website. We request those centres to return the questionnaire by email to nio.palliative.india@gmail.com or by post to the **IAPC Secretariat**. If you know any centre which is not aware of this data collection programme please direct them to the website of the National Information Office.

The directory is being made available on line at the IAPC website www.palliativecare.in

PROGRAMMES FOR CELEBRATING WORLD HOSPICE AND PALLIATIVE CARE DAY



Saturday, the 10th of October 2009, is the World Hospice & Palliative Care Day. On this day, more than 1000 events will be held in 80 countries around the world to raise awareness and funds for local hospice and palliative care services.

This year, World Hospice & Palliative Care Day has been clubbed with 'Voices for Hospices', a global musical event that circles the globe with musical concerts

For more details and registering your event please log on to : <http://www.worldday.org/>

Following are some of the activities being organised by various palliative care groups in India.

Bangalore:

Chief minister of Karnataka Sri.S Yediyoorappa will inaugurate the Walkathon from Vidhana Soudha to Cubbon Park organised by Department of Palliative Medicine, Kidwai Memorial Institute of Oncology on October 10th 2009.

People from different palliative care programmes in Bangalore, volunteers, patients, carers and others will participate in the programme. Plays and competitions are also being organised.

Sri Nagar:

Pain and Palliative Care Services, RCC, Srinagar will be displaying banners in the hospital to make people aware of the importance of World Hospice and Palliative Care day.

New Delhi:

Cansupport, NewDelhi is organising a music programme of the noted singer Dr. Madan Gopal Singh and his team at the Baha'i House of Worship auditorium. To support efforts towards caring for people with cancer, a commemorative souvenir will also be released on the occasion of the World Hospice and Palliative Care Day.

Bokaro:

'KOSISH -the hospice' in Bokaro, Jharkhand is planning a road trip all over India for creating awareness on palliative care, called "Hospice tour India", which will be flagged off on World Hospice Day from Bokaro Steel City

Mumbai:

Tata Memorial Centre, Mumbai is organising cultural programme for patients and relatives.

Chennai:

Lakshmi Pain and Palliative Care Clinic Chennai with RMD Centre for Palliative Care is organising a public awareness programme in three shopping malls in Chennai on October 10th.

Thiruvananthapuram:

Health Minister of Kerala, Mrs. P K Sreemathi Teacher will flag off a two-wheeler rally to spread the message of Palliative Care organised by Regional Cancer Centre, Thiruvananthapuram. A workshop on communication skills will also be organised on the same day.

Pallium India in association with Trivandrum Initiative in Palliative Care (TIPC) is organising a "Kudumbasangamam" for patients and their families at Cotton Hill School, Trivandrum. A bike rally by volunteers of link centres carrying the message of palliative care will culminate at the venue. Organisers of Surya Festival have agreed to dedicate the dance program by Dr Padma Subrahmaniam on 10th October at Tagore Theatre to palliative care.

Kozhikode:

The Institute of Palliative Medicine and Bank Men's Club, Kozhikode together will be organising a public meeting and cultural evening at Tagore Centenary Hall.

Guwahati:

An outpatient clinic for elderly care will be inaugurated on the World Day at Guhawathi, Assam .The clinic will run once in a week to serve the people in the nearby areas of the hospice.

Chandigarh:

A Prayer Meeting in the morning and cultural programmes in the evening will be held at the Chandigarh Hospice on the world day. An education programme and seminar on palliative care is also being organised by Chandigarh Palliative Care Society.

What Are You Going to Do on World Hospice and Palliative Care Day?

Please inform us the activities in your organisation as part of the World Day and send the photographs to The National Information Officer, IAPC Secretariat, Institute of Palliative Medicine, Medical College, Kozhikode-673008 for publishing in the IAPC Newsletter and the Website www.palliativecare.in