



# Dawn to Dusk...

## Honouring the dignity of life

Sneha Sandhya Age Care Foundation

Quarterly Newsletter January 2021

### New Beginnings

COVID19 Pandemic compounded the challenges faced by people with terminal illnesses. The lockdowns and conversion of hospitals into COVID centres had denied them access to health care. We at ACF, also had to suspend our services temporarily, in lieu of the pandemic. However, closure of one door led us to open more windows of service delivery through telemedicine & 24/7 telephonic support. Our medical team and volunteers constantly stayed engaged with our patients and their families.

During these difficult times, with the help of PRADHAMA HOSPITALS we started our Hospice in their premises with new facilities for a more integrated Palliative care service. We built electronic medical records and trained our staff to deliver quality service adapting to the changed times of post COVID 19 era.

As we move ahead in 2021, we are launching our first quarterly newsletter, reconnecting with all of you once again. We see this newsletter as a shared learning experience to one and all.



**Child deprived of his “Right to Light”**

#### *Physician’s Pill*

Children at the dawn of life are expected to grow into healthy beings while the elderly at dusk of life are accepted to develop terminal illnesses. However, this belief doesn't always hold good.

Genes, the building blocks of life, which give us our distinct identities sometimes go faulty and cause inherited disorders in children, that claim their lives very early. One such rare inherited disorder is Xeroderma Pigmentosum – dry pigmented skin. It appears in infancy or

## Palliative Care in genetic disorders

early childhood as a severe sunburn usually after a short exposure to sunlight.

This is an autosomal recessive disorder, which means that the parents are asymptomatic carriers, each carrying one normal gene and a faulty gene for this condition. The affected child inherits one faulty gene from each of the parent. Normally when skin is exposed to the sun the ultraviolet rays in the sunlight damage the DNA in skin cells. This damaged DNA is repaired and replaced so that the skin remains normal. In patients with Xeroderma Pigmentosum, the genes responsible for DNA repair are faulty and the damaged DNA cannot be replaced resulting in dry pigmented skin which may turn into skin cancer.

By two years of age, almost all children with XP develop freckling of the skin in sun exposed areas - face, neck, arms and lips. As they grow, the pigmentation increases, dark and light colored spots appear giving rise to the *salt-pepper* pattern of skin.

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## Child deprived of his "Right to Light"

### Physician's Pill

The eyes of children with XP become painfully sensitive to sunlight, eye lashes fall out and eyelids turn inward or outward. Some children develop white, scaly, highly chapped lips, white & red patches and ulcers inside the mouth. About half of these children develop skin cancer by the age of ten. These cancers occur mostly on face, eyes, eyelids, lips, tongue, scalp.

Some children develop hearing loss, difficulty walking, mental retardation, difficulty in swallowing, talking and seizures. There is no cure for Xeroderma Pigmentosum.

These children and families will benefit enormously from palliative care, from the very time of diagnosis.

We must help them improve their quality of life and life expectancy.

After all, "**Every child has the right to light and life**".



### Nurse's Balm

A sixteen year old boy presented to our hospice with a large wound covering his right half of the face, from forehead to the chin; there was no right eye visible. He was screaming in pain saying "God why are you doing this to me, give me something and kill me, I can't bear this anymore".

When he was 8 months old, he had sun burns which developed into dry pigmented skin. His parents coming from a village, daily laborers ran from hospital to hospital, skin ointments were prescribed but no recovery. In 2019, he developed a tumor on the left cheek for which he underwent surgery on face, ear, and jaw followed by a skin grafting. In 2020 he developed similar problem, this time on the right side of the face for which he again underwent extensive surgery. Now he came to us with a diagnosis of **Xeroderma Pigmentosum, Squamous Cell Carcinoma and Malignant Melanoma** of right eye, for pain management and wound care. He was depressed about his appearance, wanted to stay alone, not talking to others, reluctant to take photos, not wanting to have wound dressing or take medications.

His pain score was 8/10. The procedure of wound dressing was very much painful and embarrassing to the patient. After much convincing and administration of MORPHINE half an hour before the dressing, we calmed him down and cooperate for the wound care. The nursing team in every shift would play indoor games with him.

Through this '**encouraging diversion and recreation**' approach of ours, we could improve his communication with us and everyone around. He would ask us many doubts and express his feelings. He told us "Sisters, you are gentler than the nurses in the earlier hospitals I went to". After twenty days of hospice care he went back home, more cheerful and calm, with a pain score of 2/10. We told his parents to spread the word in their village that no one should neglect sun burns, one should protect oneself from sun because it can lead to skin cancer.

We learnt that our **nursing balm** gave him relief unlike the skin ointment prescribed earlier.

We said aloud once again "**Its every child's right to be pain free - ZERO TOLERANCE to PAIN**".

Early diagnosis and extensive sun protection can prevent skin cancers and prolong their life expectancy. Children with Xeroderma Pigmentosum and their families face many challenges in daily living.

These children have considerable pain from their skin, eye and oral lesions. They will have bad oral hygiene and difficulty feeding, that needs special care.

Most importantly these children will have lot of psychological issues like anxiety and depression due to poor body image and self-image. The family also experiences severe grief from the knowledge that their child is having a life limiting illness with no cure.



## Delayed developmental milestones, a normalcy or.....??

### Physician's Pill



Developmental milestones are skills, which most children exhibit by a certain age, like rolling over, crawling, sitting up, taking the first step, smiling for the first time and waving bye-bye. There is a norm to when these milestones will happen based on the development of the brain, but they may vary in different children. This variance is always not normal and can be due to rare genetic disorders in children called Tay-Sachs disease and Batten disease or Neuronal Ceroid Lipofuscinosis {NCLs}.

**Tay-Sachs** disease is a rare disease that a child inherits from its parents who are asymptomatic carriers. These affected children will have a faulty gene, resulting in the absence of the enzyme {Hexosaminidase A} that helps break down fatty substances. These fatty substances, called GM2 gangliosides, build up to toxic levels in the child's brain and affect the function of the nerve cells. Most infants with Tay-Sachs disease have nerve damage starting in the womb {before birth}, with symptoms usually appearing from 3 to 6 months. Progression is rapid and the child may live upto the age 4 to 5 years.

The symptoms include: baby can't roll over, crawl or sit; increased startle response to normal sounds; deafness, progressive blindness, and cherry-red spot on the macula {an oval-shaped area near the center of the retina in the eye} decreased muscle strength, paralysis, muscle stiffness, seizures [fits] and delayed mental and social development.

We made a special reference to these genetic disorders in children, in our newsletter because we identified three children, with these illnesses, recently in our community. We wish to spread awareness about these incurable disorders, which can go unrecognized and undiagnosed {due to their rare incidence} more so in the rural communities due to lack of awareness.

Convulsions and recurring respiratory infections leading to severe breathlessness can be the emergency symptoms requiring repeated hospitalizations.

The disease is most common among Ashkenazi Jews, whose families descend from Jewish communities in central or Eastern Europe. Approximately 1 in 30 people in the Ashkenazi Jewish population are a Tay-Sachs carrier. There's no way to prevent the disease.

Genetic testing can be done to see if the parent is a carrier or if the foetus has the disease. Pre-natal tests such as chorionic villus sampling {between 10 &13 weeks} and amniocentesis {between 15 &20 weeks} can diagnose Tay-Sachs disease. An affected child is diagnosed by clinical examination, family history, enzyme analysis using child's blood or tissue samples, and an eye exam may reveal the red spot on the macula.

**Batten disease** is the common name for a broad class of rare disorders inherited by children from their parents who are asymptomatic carriers. It affects the function of tiny bodies within cells called lysosomes. Lysosomes are the 'recycle bin' of the cell and break down waste products, proteins and naturally occurring fatty compounds called lipids into smaller components that can be discarded out of the cell or recycled. In Batten disease/NCLs the defective genes do not produce the proper amounts of proteins important for lysosomal function.

These proteins are needed for brain cells (neurons) and other cells to work efficiently. The lack of a functional protein causes the abnormal build up of the residue called *lipofuscin* in the cells. These lipofuscins poison the cell eventually killing them.

This disorder manifests between the ages of 2 and 5. The symptoms are usually failure to reach normal milestones, slowing of head growth, inability to grow in an age-appropriate manner, vision loss and seizures. These children become completely dependent by age 3, unable to communicate or feed themselves. Microcephaly or an abnormally small head, can also occur due to brain atrophy as nerve cells die. At present there's no cure for Tay-Sachs disease or Batten's disease. Typically treatment is supportive, focused on reducing symptoms and improving the quality of life for the patient and family through Palliative Care.

Palliative care will include: medication for pain, anti-epileptic medications for convulsions, physical therapy, nutritional support, and respiratory treatments to reduce mucus buildup in the lungs.

Emotional support for the family is also important. Taking care of a sick child is emotionally challenging. Seeking out support groups and talking with other families managing the same disease can be comforting.

**Care beyond Cure** is the prescription for now.

## Care beyond Cure – HUM RAHI – Pallium India

We began 2020, with sensitization of the medical fraternity to Palliative care, across the state of AP along with our friends from Australasian Palliative Link International {APLI} – Dr. Christine Drummond, Senior Consultant and Dr. Seshu Boda, Family Medicine Physician. The participants were: students and faculty from GSL Medical College, Rajahmundry, GEMS Hospital, Srikantham, Sri Padmavathi Medical College, Tirupati, Doctors and Nurses from Jayabharath hospital, Nellore and KIMS-ICON hospital in Visakhapatnam.



## COVID LOCKDOWNS – CONTINUUM OF CARE

We had to temporarily suspend our Hospice services but continued telemedicine support 24x7. Our home care visits to patients who were in dire need of our services were gradually resumed and also dispensed Morphine to the patients requiring the same. We continued with dispensing medicines to the elderly in the old age homes and in the community.



## Braving the challenges of COVID - Care Campaigns Community Outreach

**NUTRITION** – During the COVID lockdown, we provided packed meals to patients and attendants of two Hospitals, Mahatma Gandhi Cancer Hospital and Govt. Gosha Hospital, Vizag, 200 – 400 meals per day, in the months of April and May 2020. Renewal / Restoration of our services began slowly, following the COVID protocols through home visits and geriatric clinics in the community.



## ADAPTATION TO A NEW POST COVID PANDEMIC ERA:

As the COVID pandemic started abating, we incrementally expanded our services, adapting to the new COVID protocols.

## REMEMBER THOSE WHO CANNOT REMEMBER - Let's talk DEMENTIA

The month of September {World Alzheimer's month} saw us engaging with the community and advocating Dementia care. In collaboration with ARDSI VIZAG and ARDSI Hyderabad Chapters our volunteers organized webinars, AIR talk shows where our Physicians explained about Dementia care, role of Palliative care & Alternative therapies in Persons with Dementia. With the help of Vizag Municipal Corporation, we spread awareness through display on digital Billboards.

## PRADHAMA – Age Care Foundation HOSPICE

On the auspicious day of Vijayadashami {25.10.2020} we started our hospice services at Pradhama Hospital, who have given us space for a twelve bed facility, free of cost and enabled us to provide an integrated palliative care service.



## MY CARE – MY COMFORT – Palliative Care.

In the month of October {World Hospice Day} we organized webinars and Radio Talk shows and educated the medical fraternity and the community about how every patient suffering from an incurable illness had a Right to Quality of Life, through integration of palliative care into his treatment from the time of diagnosis.

## Always remember the Zebras!

My journey started in January, 2017. In spite of our best efforts, my 1-year-old son was unable to walk independently. More worrisome was the fact that he was regressing, losing abilities that he had earlier. After numerous visits to doctors, we finally found answers at a neurologist's office in Hyderabad, where he was diagnosed to have Tay - Sachs disease. We were shocked to learn that our son was not going to have a long life.

Till then, I did not know there were so many rare diseases without treatments. I assumed like most people, that cancer was the only disease without a treatment. Sadly, this is not true. The burden of rare diseases in India is huge.

We faced many challenges in caring for our son, not knowing what the treatment options were. After a couple of years of struggle, we realised that there is no cure for my son's illness. However, he still had every right to a dignified life, one that gives him comfort even if he is dying. That was when we brought our son under the fold of Palliative Care.

### Care Giver's Diary

I'd like to say to fellow parents/patients fighting life limiting diseases, to be united and fight for the right to receive compassionate care. Meet and work with others to draft and influence government policy.

Do not hesitate to ask why? Why should my child be condemned to a life of pain and me to a life of hopelessness? Why cannot my child or I, have **access to care that improves quality of life?** You are your child's voice, the only hope they have! You must stand up for what is **RIGHT** if you want to be proud of what you see in the mirror looking back at you. Say something and do something.

The Zebras are brave animals that care deeply about their group members. When a zebra is wounded by an attack, the other zebras come to their defence, circling the injured individual and attempting to drive the predator away. They are strong, protective and resilient society that takes care of its own

To all of us I say - "Always remember the ZEBRAS".



## Carroms an *adjvant* to Codeine

I stepped into the day care unit of our palliative care center. I saw a mother teary eyed, pleading her sixteen year old to get the wound dressing done. The child was agitated, throwing things around, refusing any care and just wanted to go back to his village. I couldn't see the boy's eyes or any facial features, except for a large gory wound covering the entire face. The nursing team was trying hard to counsel him, how important it was for him to have the wound dressed and take pain medication. I could feel the pain looming large in that room, the worried mother, the anxious child and the frustrated nurses, all wanting to alleviate the child's suffering, but helpless. As someone trained in social work and communication, I had to do something to make the child see reason and co-operate.



I walked up to him, held his hand and gently asked him what was his favorite game; he couldn't see me because of the wound on his eyes and face, he could only hear to my voice and feel my touch. He tried to wriggle out but I held on gently but firmly. He said "I like carrom board game". I brought out the board games that I had stacked in the center, but he insisted on carroms.

I hurried to the nearby play store and brought the carrom board and sat down for a game with him and his mother. After the game he walked to the treatment room, had his dressing done and got admitted into the ward for care. When I learnt from the doctor that the boy had a skin cancer which started from a simple sunburn because he had a genetic disorder, I was shocked - a simple sun burn to skin cancer. After that day, I would play a game of carroms with him every day, realizing the impact of play therapy, I learnt as the non-pharmacological methods of pain management in children. As we played, he would share with me how much he loved his life in the village with his grandmother, his friends there and wanted to go back. My carrom board game also opened my channels of communication with his parents and share their pain and grief.

Yes indeed, **Carroms** worked as an ***adjvant*** to **Codeine** and I must say it gave much more pain relief to my friend with xeroderma pigmentosum and skin cancer.

**Myth # 1: I need a Pap Smear test every year.**

**Truth:** If your Pap test and HPV test are both normal, you don't need to get a Pap test every year. Cervical cancer screening guidelines for women with a previous normal Pap & HPV test result.

Ages 21 – 29: Pap test every three years;

Ages 30 – 64 years: Pap test and HPV test every five years;

Ages 65 and older: A well-woman check up every year. {HPV- human papilloma virus}

**Myth # 3: Persons with dementia don't understand what's happening around them.**

**Truth:** Persons with dementia struggle to communicate effectively; this does not mean they are unaware of what is happening around them. The part of the brain which deals with communication is separate from the area which deals with awareness. This means that sadly most do have thoughts to communicate although they struggle to relay these.

**Myth # 2: Children do not understand death.**

**Truth:** Children begin to grasp the finality of death around age 4. Children under 3 don't understand the irreversibility of death, they talk about dead people as if they went on a trip or took a nap or will say that dead things can come back to life with help of water, food, medicine or magic. Children between the ages of 5 and 7 understand the other two aspects of death: Non functionality - the idea that a dead body can no longer do things that a living body can do. Universality – Every living thing dies, every plant, every animal and every person, including oneself.

**Myth # 4: If I take morphine, I will become addicted.**

**Truth:** Very few people who use morphine for pain relief, ever become addicted or psychologically dependent.

However, it is important that anyone taking opioids for more than two weeks should not stop all of a sudden.

Also, Morphine taken in the doses for pain relief doesn't cause respiratory depression.

**Music Therapy –**

Can help to relieve pain and reduce stress and anxiety for the patient, improve respiration [oxygen supply], lower blood pressure, improved cardiac output, reduce heart rate, and relax muscle tension. Best for children with cancer, mental illness, Dementia, sleep disorders, Schizophrenia etc.

**Brain Aging –**

Walking 10,000 steps or five miles per day helps your brain to remain sharp. The impact from hitting our feet on the ground while walking sends a hydraulic wave upward through our bodies. This wave is actually strong enough to send blood back up through our arteries, increasing blood flow and oxygen supply to the brain. This increased blood flow to the brain is linked to better cognitive function, improved memory, and overall protection against brain decline. Walking on hard ground is more effective than running or cycling.

**Photo Aging –**

Premature aging of the skin resulting from exposure to sunlight {UV rays} and skin cancer can be prevented by the application of sun screen containing zinc oxide and or titanium dioxide, every day. Sunscreen containing DNA repair enzymes help undo previous damage. Vitamin C and E and green tea antioxidants help brighten dark spots.

**Brain Foods –**

Blue berries, strawberries, gooseberries, walnuts, hazelnuts, almonds, cashews, peanuts, sunflower seeds, sesame seeds, whole grains, wheat germs, dals, black beans, pomegranates, avocados, freshly brewed tea, dark chocolate, salmon fish, fish oil are some foods that will provide antioxidants, omega3 fatty acids and vitamin E, which will promote healthy brain function and may prevent age related memory loss.

## Caring for the elderly at their doorstep

Unattended chronic disease, unaffordable medicines and treatment are part of old age life in India. Lack of financial independence, physical disabilities and difficulty in reaching the health care facilities are some of the important barriers for elderly people to access health care.

One of the foremost objectives of Age Care Foundation is to take basic health care services to the door step of senior citizens. To fulfil this objective the foundation has chosen two tracks. The first is to conduct monthly clinics at all old age homes in the city for the benefit of the inmates. The other is to conduct monthly clinics in different parts of the city of Visakhapatnam for the benefit of elders living in the community. All clinics are conducted in coordination with the local communities or NGOs working in that area. Keeping in view the future plans, one rural and one tribal village were also chosen for the out-patient clinics as pilot project. All patients with chronic diseases, who need long term care are registered and medical records are maintained in physical and digital formats. Weight, Blood pressure and Blood Glucose are tested during every visit. All services and also one month's supply of essential medicines is provided free of cost during the visits. The clinics are conducted by a team comprising of doctors, nurses and volunteers.



Volunteers play an important role by checking the compliance of treatment by taking detailed history and also verifying the empty wrappers of the medicines dispensed. They also spend lot of time in educating the patients regarding diet, exercise, treatment compliance etc.

Contrary to general belief, most of the patients value these services very much in-spite of them being free. Some of them keep donating small amounts to help the foundation sustain and expand its services. The attendance to the clinics on an average exceeds 85%. Patients needing investigations or specialist care will be referred to other centers as per the need. Home care visits are provided to select patients who are non-ambulatory.

On an average every month, we serve about 1000 patients through out-patient clinics and another 200 inmates through old age home visits. Hypertension, Coronary artery disease, Diabetes, Osteo-arthritis, Hypo-thyroidism, Stroke are among the chronic ailments with which these patients present themselves. Barring the lock down period, our staff and volunteers conducted these clinics even during the time of Covid-19 pandemic.

### **Compliance comes with Cost:**

During the last eight years, we have observed that satisfactory control of blood glucose and blood pressure can be obtained by using generic drugs which are available at affordable prices. We also found out that sometimes patients did better on inexpensive

medications compared to much more expensive regimens they were following previously. Earlier because of the high cost of medicines, they were not purchasing the full quantity of medicines required for

the month and they were not using them during the later part of the month. But now either because of free supply or affordability of the medicines prescribed, they were using the

medicines throughout the month, at full doses as prescribed by the physician. Counselling by volunteers during every visit also contributed to the better outcomes.

Through these services the foundation is able to provide basic health care along with medicines completely free of cost to the inmates of many old age homes and also to many underprivileged elders living in the community. We have also been striving to create awareness in the community about physical and mental health concerns of the elderly and to this end, conducted programs for the managers of old age homes in collaboration with the Nightingales Foundation, Bangalore, for the National Institute of Social Defense under Ministry of Social Justice and Empowerment.

In the coming days, we are looking forward to further improve the range of services provided and also to expand these services to more locations in the city, so as to serve many more needy persons.

### **FACT FILE**

#### **Palliative Care**

Total no. of patients cared for up-to 31.12.2020 -	<b>2,346</b>
Home Care Visits (Started in Apr-18) -	<b>2,537</b>

#### **Geriatric Care in Dec – 2020**

	No of Persons Served
11 Out Reach Clinics -	<b>1092</b>
6 Old Age Homes -	<b>253</b>