



eBulletin

ARDSI CALCUTTA CHAPTER

Providing Dementia Care & Service since 1999

December, 2015

From the desk of the Secretary, ARDSI Calcutta

Dear Friends,

Warm greetings from ARDSI Calcutta family. It has been a while, precisely a year since we came out with our last e bulletin in November 2014.

Much has happened since then, and we thought you would want to know how we did. So, here is our share and we sincerely hope to hear back from you your views and suggestions on what we might do more to reach our people with dementia and their families we represent.

We choose pictures mostly to reach you this time as we believe pictures are more than thousand words and in our area of dementia care, it's a more appropriate and powerful way of communication.

We also highlighted two articles, one from a family caregiver on the theme of this year World Alzheimer's Month, "Remember Me", and the other from one of our young intern at the care center with a sincere hope that we can encourage more family caregivers to share their thoughts and motivate troupes of young people to come forward to make the connection with people with dementia.

We also had to bid our final goodbye to Brigadier S P Bhattacharya, a family carer and a Board member of ARDSI Calcutta. Our prayer for God's choicest blessings for his soul to rest in peace. He had been a pillar of strength in the journey of dementia care for his wife and we believe that he will continue to inspire us all as we continue to walk in our caring journey. Do remember, Brigadier that we LOVE YOU MUCH.



Wishing you and your family a great holiday season and a peaceful new year ahead. Stay safe and warm.

Nilanjana Maulik
Secretary, ARDSI Calcutta

Remembering My Parents

By Suparna Bose



They met as colleagues in the office of the Account-General West Bengal, Kolkata, in the beautiful red-brick building on in 1961. Later they found out that they both were members of the Calcutta Cine Club. They watched Fellini, De Sica, Bergman, and were fans of Hollywood movies as well. One thing led to another and they got married on August 15, 1963. It was an inter-caste marriage and it ruffled a lot of feathers in both families. They were unceremoniously dumped by their families and started their married life in a small apartment near Dum Dum Airport. They were happy on their own, went out for extended honeymoons twice a year to a small rural place called the Mandar Hills. My father suffered from severe gastritis and so my mother gave up eating fried food. She cooked non-fat, low-fat healthy food all the time and never had a cook till she was diagnosed with cancer in 2008.

They had me after six years of marriage. The night before she delivered, they had gone to see a Hollywood movie. My father was the first one to see me, and my mother asked him if the baby had a fine, high nose. She was a little ashamed of her snub nose and Baba always teased her about it! When I grew up I took on that mantle and reminded her that the Rajdhani Express must have run over her nose at least twice. She tolerated the jokes stoically.

Baba was a savvy shopper, who liked to visit at least five to ten shops, had the salesperson bring out at least fifty or more items before he found the chosen one, and then bargain. Ma would go to one high-end shop, look at the items without bothering the salespeople too much and would choose any number she liked. He had a smiley face, loved interacting with people, knew every shopkeeper, rickshaw-puller or neighbor by name and family details. She had very few friends, never looked at anyone around her when she went out for office and very few people in the neighborhood knew her. The few who knew her seldom dared to talk to her. He went to most of the PTO meetings and the teachers used to gush about how well-spoken he was. She might have been to two and both ended disastrously, with her pointing out errors in the teacher's corrections. He loved Uttam Kumar, she loved Soumitra Chatterjee. But they both loved Tagore and Rabindrasangeet, Satyajit Ray and Ritwik Ghatak. The only Bengali movies I was allowed to watch were by the last two

directors. Whether I understood those movies or not was a different matter. I also remember getting new clothes throughout the year, never ever during festival times like Durga Puja. My friends envied that.

Ma gave me a lot of freedom while I was growing up, as a teenager. Baba was definitely more conservative. When I was in tenth grade, our school had arranged for an excursion to Delhi, Agra and Jaipur. Baba said no, but my mother wanted me to go. She told me to ask my class teacher if her signature would be okay. My class teacher agreed, after I assured her that there won't be a lawsuit against her! The night before we were supposed to leave, Ma told me to take the suitcase out, and keep it open on the bed. Baba returned at 10.40 pm, his usual time, saw the scene, realized what had happened and then started asking me questions about which teachers would be accompanying us and so on.

I always had freedom to choose what to wear, which school to apply, which subjects to choose, even, which test to take. Looking back, I see that initially I was too young to have understood the responsibilities that freedom came with and might have taken a number of wrong decisions at different times in my life. However, it gave me a unique sense of independence and self-confidence later on in life and influenced me profoundly. I feel that I am a better person for having known freedom and realizing how much it meant. They both also trusted me implicitly. When I was in college, one of my friends needed some money. It was important and I asked Ma and Baba for it. They never asked what my friend's name was, or why they needed that money. My word was enough for them. Always.

Baba always took me to the market, so that I knew how to look at vegetables, fruits and fish and choose the freshest ones. How the flesh of the fish should be firm, the gills blood-red, not dark red, the eyes bright and glistening. How to pick tomatoes gently, check the eggplant for freshness. How to make friends with the produce sellers, call them "Uncle", "Aunt", "Sister" or "Brother", to respect them as fellow human beings. Ma never ever touched the produce when we bought them home. Baba and I washed each vegetable, or slices of fish or meat and prepared them so that Ma could take over and cut the vegetables. Each piece of potato or eggplant or pumpkin should be identical in size, no misshapen ones. The coriander leaves, *methi* leaves and spinach had to be meticulously arranged, leaves in one pile and stalks in the other. When she cooked them, ma would diligently cover the wok with a plate, so that the stove stayed clean. When she prepared rice, she put a bowl of water on top of the vessel, so that the water would be warmed by the steam. That saved energy, and she would always put warm water in the curries, so that cooking temperature remained the same.

When I was ill, they took turns in massaging my body and feet. Ma made me tasty chicken soup and one time, I remember her hugging me as six blankets lay on top of and still I shivered. I had malaria. When Ma had chemotherapy, Baba nursed her back to health. Baba also knew all the compounds of the medications by heart.

They had fights, everyday ones, serious and earth-shattering ones. They had their good times and bad times. But they stayed together, for forty-nine years, till Death took Ma away. Baba is there, with a steadily declining memory, a shadow of his former buoyant self. But he is still there. And she is there too somewhere. They will be there for me. Always.

Remember me? Remember me.

By Minori Parelkar

(Aged 16 and a volunteer in summer 2015 at ARDSI Calcutta Dementia Daycare center)

As a person who "suffers" from short term memory loss, I understand the frustration that comes with it. That little nagging in the back of your head, that tickle on the tip of your tongue, that minute forgotten thought, and suddenly your whole world surrounds it. For a while, I believed that this was how the majority of those in my shoes felt as well.

But the reality is, that what I experience day-to-day on such a minor scale, a whole community faces the same, if not worse, on a much more major scale. Those little tugs at the back of my mind are much more like heavy weights in the mind of a dementia patient, alternating with a constant whirlwind of voices and background noises. And it was at the daycare for Dementia patients run by ARDSI Calcutta where I was introduced to the gravity of this situation.

Five or so years ago, my grandfather was wrongly diagnosed with Parkinson's. Finally a few years later, doctors were able to correctly diagnose him with Dementia, and once his medication changed and his behavior shifted, things seemed to be a little less tense.

But worry still swirled through my thoughts: when I heard my mother on the phone discussing his condition with the current doctors, when I heard her and my aunt sharing whispers on the couch, and especially when we came to India this summer and my grandfather mistook me for my cousin, my 12 year-old, male cousin, compared to my 16 year-old, female self.

One thing I recall doing a lot with him were small memory games, testing him on family names and previous places we've visited. "Remember me?" was a question I used quite often.

"Remember me? What's my name?" Every other day it was the same question. And every other day it was a different answer: Mithu, Rinku, Adi, Mini, and sometimes he would get so frazzled that he just would not answer at all, instead he'd think I was some sort of employee of a bank who could reassure that all his money was accounted for.

So when I went to the daycare to volunteer for my summer this year and I was afraid the same thing would happen to me there too, that I wouldn't be Minori, that I would just be another bank accountant, perhaps even a maid this time. And so when I finished the first day, even though I felt this sense of accomplishment and a little bit of hope that the rest of the month would go just as smoothly, that anxiety still stayed. And it was so crippling that I almost couldn't bring myself to go back the next day. Of course, my mother wouldn't allow that, so as I walked through the door that next day, it was immensely reassuring to see the smiles directed towards me.

"Wasn't she here yesterday?" "The one from America?" "The one with the father from Mumbai,"

I don't think I had ever felt my anxiety vanish more quickly than it had that day. But it returned almost immediately when I sat down in front of a patient to engage in simple conversation. I was worried my language crutch would hold me back, that

I wouldn't be able to hold their attention with my broken Bengali. As it turned out, I didn't need to. I sat in front a man who was previously some sort of income collector and though he brushed off my first few questions, the minute I introduced myself with a *Namaskar*, his whole demeanor changed. All of a sudden he was spilling out words so fast I could hardly keep up. And when I could, I realized he was giving me information on how to greet people and lead them into his office. He was treating me, almost as if I was his secretary.

So I went along with it, I asked him for further clarification, where exactly to bring clients in, but I was still immensely confused, where was the office, what was he talking about?

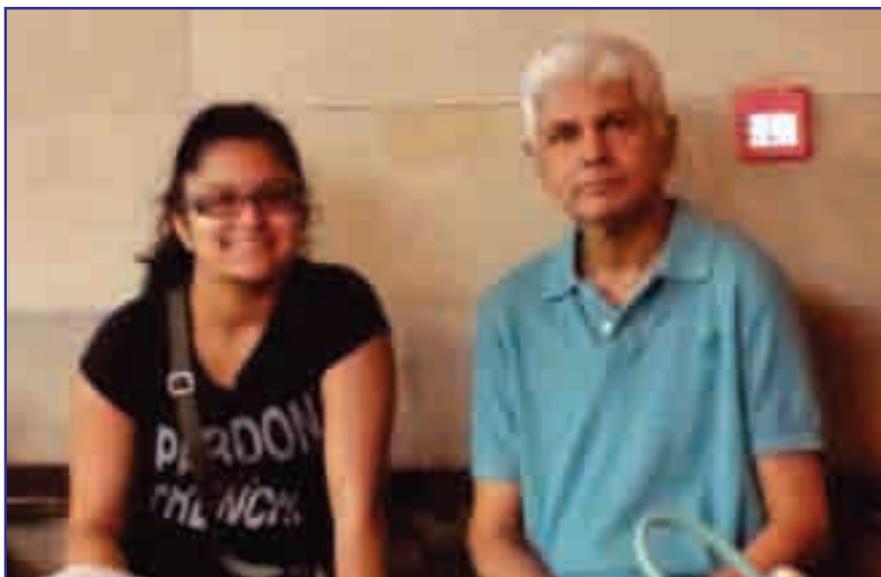
Later in the week I attended a training conducted by the center where it was explained to me that patients often believe they are in a place they are familiar with, such as a work place, or their home. And if what they say seems like gibberish to you, it does make sense to them, and the best thing to do is respond diligently.

So it was the weekend after my first week there when I started to think about what I had learned, from watching the staff & volunteers at the daycare and began to relate that to how I was responding to my grandfather. I realized, it was better to take on the role of whatever he had given me, be it his granddaughter or his bank accountant, if only to put his mind at ease.

With this in mind, life suddenly seemed to be traversing a lot more smoothly. When he asked where his money was, I told him it was safely stored in his account, and if he'd like, I could show him the records. When he asked me how school was going, I told him things were going pretty well, and that my grades would make him happy. When he asked me where I went every morning, I told him I had taken up a job, and he didn't have to worry. When the worry lines were replaced with a gap toothed smile I saw that it wasn't such a big deal taking up a role. I wasn't any less Minori, I just took on a couple of roles: an accountant, a secretary, a caregiver-in-training.

So early in August, when I was standing at the airport, and I hugged my grandfather good bye I said, "" Remember me.

A statement, not a question.



Minori with her grandfather

Activities at a glance since December 2014 at ARDSI Calcutta

Report by Nivedita Saha
Program officer- ARDSI Calcutta

Awareness programme : We conducted in total 15 awareness programs all over the city and suburbs from December 2014 till date.





Carer Support Meet : There were 7 meets conducted since last year.



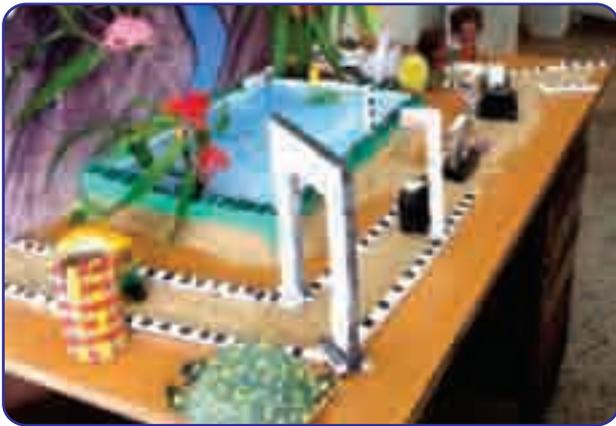
Daycare Activities : The total number of clients who attended the day care center from December'14 till date on an average were 18 and a total of 300 days of care delivered. In general we plan out various daycare activities for the clients as per their physical ability, interests, likes and understanding. We also celebrated each festival with rituals and in all its colour and fancy.

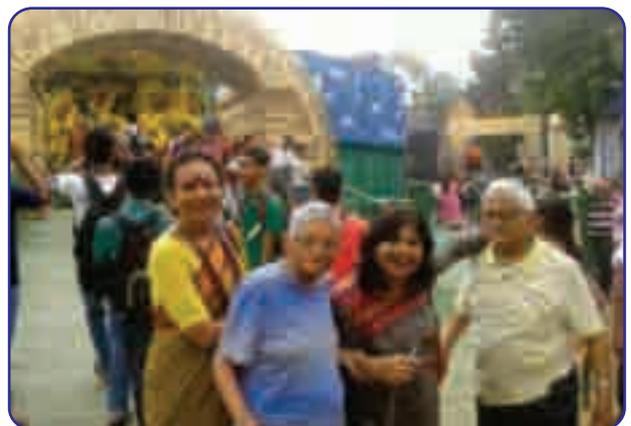




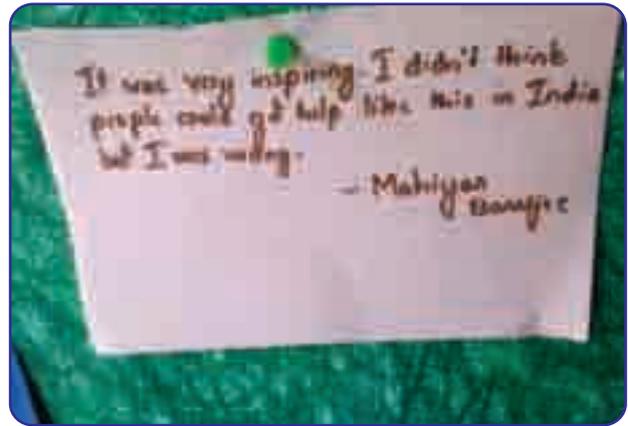












HOME COMPANIONSHIP : We extended our Home Companionship service to 8 clients per month since last year and a total of 288 days of care activity was delivered.

Office Visit : From the month of December'14 till date 47 Office visits were conducted to extend careplan and counseling to families.

Home Visits : From the month of December'14 till date 35 home visits were conducted to provide counseling and training to families taking care of dementia persons at home setting.

Training : 7 training programs on dementia care conducted in house and in association with other social service organizations.



Visitors : The center activities were visited by three interns, Ankhi Maulik, a student of Boston University who focussed on engaging with persons with dementia through music therapy sessions. She filmed sessions for ongoing project on “effect of personalized music on persons with dementia's mood, behaviour and physical vitals. Another young intern was Minori Parelkar, a high school student from New Jersey, USA who focused on communication of persons of dementia with younger generation. The third intern was Tapadhir Das, another high school student from Oregon, USA who focused on innovative ways to reach and raise awareness of dementia in the community.



Two other interns who just started their work is Shreya Nondol from University of Calcutta who is looking into effect of environment on family members with dementia and the other Haimanti Sen who will be looking into the quality of life of dementia persons in a daycare center.

Besides the interns we had three groups of Nursing students from Surgical Nursing and Mental Health Nursing background who came for understanding the daycare environment and gain understanding of dementia persons.

Memory Clinics : A total of 8 clinics were held at our Kolkata center and a total of 42 in our Chandannagar Memory Clinic run in Dishari Hospital at present.

Our Chandannagar campus: In order to extend our service to semi-urban and rural areas, we have planned to set up a centre for early diagnosis and care of persons with dementia in the land so kindly donated by Sri Bholanath Das in Chandannagar. This centre will comprise of an epidemiological unit, neuropsychological unit, a genetic cum biochemistry unit and a care center. Epidemiological unit will carry survey among populations to detect the number of cases with dementia. Neuropsychological unit will help to determine the abnormality of brain functioning in terms of different components of intelligence affected in suspected persons. Similarly, possible genetic research might explore the underlying cause for developing dementia. The care center will cater to care and support for the person with dementia and their families in the neighbourhood.

Here are some recent pictures of the building work in progress.



Reflection

By Arpita Dutta

'Dementia' as known to the general population is still a disease affecting the memory but for people living with it, it is a devastating experience altogether. A disease which is yet to find a cure for itself makes it even more traumatic.

ARDSI, Calcutta chapter, is one of it's kind of organization that comes as a savior to the much needed people affected with this disease and I had all the privilege of working there as a volunteer first and then as a staff. Engaging with clients in regular morning activities like reading books, solving puzzles and doing crafts work made me realize that there is still lot more left in them even though it seemed to be over. Musical sessions brought new ease of life in them and I found them happily clapping, singing and dancing together, living every moment to the best way possible . I also got the opportunity to meet clients face to face along with their families through memory clinics, monthly carer support meets and home visits helping myself to understand the ground difficulties a person having dementia faces in their everyday life. Conducting awareness programmes for the masses and training for people keen to work in this field was one of the top priority job that equipped me to actively participate in the urge to create a dementia friendly community at large.

'Dementia' is an area which demands immediate attention of everyone - right from the government to that of the general public. People must come forward in lending their hands by creating awareness and supporting the affected people and their families in living a life of dignity and peace. Working for the cause, will not only make us do our bit to contribute as a social being but also help us realize the ultimate happiness of bringing a smile on the faces so very needed.

Appeal for Donation

Our humble appeal for support continues. The limitations of finances remain perpetual and formidable obstacles for our society. We will appreciate if you could support the urgent cause of tackling dementia through our awareness, training, care-giving and research work.

Caring for this affected population is a joint effort of all those who can still reason and remember.

We truly believe you share the same thought and will join us in our mission as others have in their various capacities through remembering us in their “Will” or on their “Loved ones birthdays or death anniversaries”. Below, we have shared some contributions made to our cause.

Donation by Hazel Platts, Ex- Board member, ARDSI Calcutta

Dear Nilanjana,

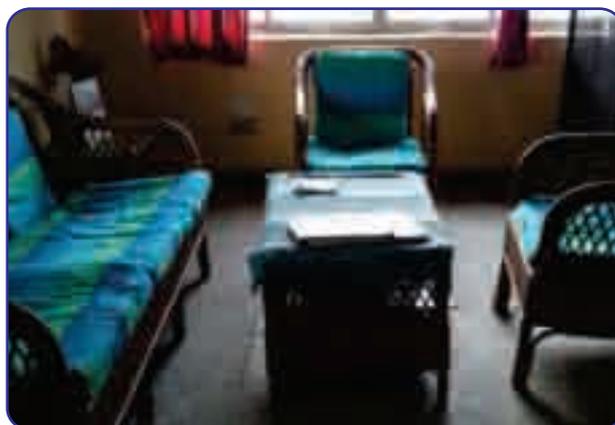
As you know Hazel passed away on the 22nd of August 2014. She has named ARDSI Calcutta as one of the beneficiaries in her will.

Thanking you,

Regards,

Vimla Subaiya

Contribution made to our daycare center office décor by Shraddha Oza, a volunteer of ARDSI Calcutta



Donation by Ms.Dhun Ayrton, ex-life member, ARDSI Calcutta

The President, ARDSI
Alzheimer & Related Disorders Society of India,
Calcutta Chapter
15/3C Naskarpara Lane, Kolkata-700031

Dear Madam/Sir

ESTATE OF (Late) MRS. DHUN S. AYRTON

We are pleased to inform that your organization, Alzheimer & Related Disorders Society of India, Calcutta Chapter is one of the beneficiaries—as per the will of the (Late) Mrs. Dhun Sammy Ayrton, former resident of Kolkata for running the Kolkata Day Care Centre.

Please note that your Cheque or draft should be in favour of "ARDSI Calcutta Chapter" if you wish to donate for our cause.

For donations via bank transfer to ARDSI Calcutta Chapter within India;

Beneficiary Name : ARDSI Calcutta Chapter

Beneficiary Account Number :10598348576

CIF No. 80469153287

Branch Code : 93

Beneficiary IFSC Code : SBIN0000093

Beneficiary Bank Details : STATE BANK OF INDIA

JADAVPUR UNIVERSITY Branch

RAJA SUBODH MULLICKROAD, KOLKATA

For donations to the Research fund/Chandennagar Facility send it to;

Savings Account Name: ARDSI CALCUTTA RESEARCH FUND

A/c No. 32861811671 at State Bank of India, Ballygunge Branch

IFS code is: SBIN0000018.

For donations from abroad to ARDSI Calcutta Chapter send it to;

Savings Account Name: ARDSI CALCUTTA

A/c No. 11000018154 at State Bank of India, Ballygunge Branch

Swift code is : SBININBB328.

ALZHEIMER'S & RELATED DISORDERS SOCIETY OF INDIA (ARDSI)
CALCUTTA CHAPTER

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WEST BENGAL PHONE: (033) 3201-7044

EMAIL: ardsikolkata@yahoo.co.in

WEBSITE: www.ardsikolkata.org

**All donations to ARDSI Calcutta are eligible to Income Tax Relief
under 80G applicable in India**

**ARDSI Calcutta is also registered under FCR ACT 2010 to receive
donations from abroad.**