

LIVING IN SILENCE, WITH A SMILE



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A short story based on a family with a sufferer of ALZHEIMER'S disease.

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Dedication

“This work is dedicated to my wife Saraswathy who is a sufferer of Alzheimer’s disease since early 2002.”

“The saddest day in my life was the day when my wife asked me if I have come to meet her husband.” This is the torturous effect of the disease named as Alzheimer’s!

Objective

The intention of my work is to raise public awareness of Alzheimer’s disease especially among the young, active and the affordable to get them involved and support the work of those who have already dedicated themselves to help Alzheimer’s patients and their caregivers.

I have introduced two characters; Himanthi, a Sinhala Buddhist girl from a well-to-do family and Jothika, a Tamil Hindu girl from a middle class family, to establish the fact that the differences such as race, religion and status matters very little, when it comes to helping someone in need. The more this reality is understood in our community the better it is for all our people.

“You don’t have to earn or hold more to help someone, share what you have, it could be even simple CARE.”

“I am Jothika – Jothi and this is my mother Kaladevi – Kala. My mother is diagnosed with Alzheimer’s disease and we are on our way to consult a Doctor at a nearby hospital.”

“Alzheimer’s? What is that disease?” Himi asked in an inquisitive tone.

Jothi said it will take a long time to explain and suggested that they meet again and have a detail discussion on Alzheimer’s disease. Himi realising that she was already late to office agreed and expressed happiness over meeting Jothi and her mother and promised to call on them soon.

One

It was Monday morning, the weather was fine, the roads were clear, most people were going about with vigour, when Himanthi – Himi, to her friends, was driving her car, which was gifted by her father Ajith Kalubowitigama, for her Twenty First birthday. She is Ajith’s only child. Himi being a music lover was looking for a particular Audio CD and did not notice, until the last moment, a young girl of her age helping an old lady to cross the road. She would have knocked them down if not for the timely signal the young girl gave Himi to stop her car. Due to the sudden application of the break, the car veered off the road and hit a lamp post causing slight damage to the car.

Himi got off the car knowing it was her fault, but the young girl came forward and said:

“I am sorry, if we are responsible in any way for this mishap.”

A surprised Himi did not hesitate to accept that it was her fault and apologized to both of them. After introducing herself, she asked who they were and if she could offer them a lift. The girl responded:

Two

Himi returned home in the evening and over a cup of tea related her experience to her mother Agilma-Agil. She had vaguely heard about Alzheimer's disease but did not know much about its effect on people. Therefore, they both decided to visit Jothi on a convenient date.

Two weeks later, Himi telephoned Jothi and made an appointment to visit them the following day.

Jothi is from a middle class family, living with her mother and a female domestic helper in a two room apartment in Wellawatte. This was purchased by her father Vadivel about a year before his death. Jothi's only and elder sister Avanthika-Avanthi is married to Hariharan-Hari and they live in Australia along with their little son Sanjeev. Both Avanthi and Hari being professionally qualified in the field of Telecommunication, earn enough to make regular remittances to Jothi who takes care of her mother comfortably.

Himi and Agil arrived at Jothi's apartment a little early.

They found Kala seated in a chair and the female helper who was standing by her told the visitors that Jothi after feeding her mother the breakfast, was having a wash and requested them to be seated. Himi went closer to Kala and asked:

“Aunty, can you remember me?”

Kala without responding to her asked the domestic helper whether her sister has come to take her to the temple. The female helper told her that she was expected any time. Himi was little confused with what was going on, but managed to ask Kala about the whereabouts of Jothi. This time, she responded by saying that she had gone for classes. Just then, Jothi arrived and on seeing her, Kala told the visitors that her sister has come to take her to the temple. Himi was emotionally upset and was comforted by her mother.

Jothi served some traditional eats prepared commonly in Tamil homes and the visitors enjoyed it. Now, more in a relaxed mood, Himi asked Jothi about Alzheimer's disease and as to when and how her mother got it. Jothi after a little thought went about explaining what she has learnt and what the Doctors have told her.

“It is a progressive disease of the human brain and it is the most common cause of dementia in the elderly. The word ‘Dementia’ means loss of one's mind or wits and is sometimes, in everyday life referred to as ‘Losing one's marbles.’

This is a three stage disease and got its name from a German physician named Dr. Alois Alzheimer who has been treating a woman named Frau Augste-D in Frankfurt, Germany.

She was admitted to his hospital with an unusual cluster of symptoms and he diagnosed her with this disease for the first time in 1901. She died at the age of fifty one in 1906.

The first stage of this disease is classified as the 'Forgetful phase.' During this stage, people with Alzheimer's disease may find it increasingly difficult to remember recent events, ultimately even those occurring just minutes earlier. Further, they end up being depended on others for direction and have a tendency to assume that things, which have been misplaced, have been stolen. Another behaviour is that they believe that people long since dead, for example, parents are still living. This stage lasts for about two to four years.

The second stage is classified as 'The confusional phase.' During this stage disorientation in time and place – confusion about date, month and year and about where he or she is. This can lead to getting lost, even in their own home. They will not be in a position to distinguish between day and night, inability to identify the family members and friends by name or relationship. Personality change from gentleness, courtesy, quietness to aggressiveness, shouting, lack of consideration for others, including loved ones and a tendency to eat almost anything like toothpaste or soap in the washroom or paper table napkins in the dining table. This is usually the longest stage and lasts for about two to ten years.

The third stage is classified as 'Severe dementia'. This is the final stage, the one which ends only in death. It can last for three or more years. A total care by others will be necessary during this stage.

The other characteristics of this stage include;

- Diminishing capacity to co-operate in activity such as dressing toileting, feeding and taking medications.
- Complete inability to control bladder and bowels.
- Disappearance of the understanding and the use of speech.
- Restricted movements, eventually immobility is permanent and in the final weeks or months the sufferer is bedfast.”

After listening to Jothi's explanation, Himi got curious and asked:

“Who will get Alzheimer's disease?”

Jothi replied:

“Anybody could get it – even we could get it when we become older.”

Jothi continued in a rather melancholy tone:

“My mother has this for almost five years now; but a formal diagnosis was made only about three years ago.”

“My father died in 2004 and about one year after his death, all my mother said and did was quite different to all that she said and did earlier. My mother was a very lovable person.

She trusted everybody and was always ready to help anyone who came to her with a problem. Suddenly she started hating people, did not want to trust anyone and chased away people who came for help. I did not take it seriously and thought things would change for better. Some people who are known to us said that her behaviour change was due to my father's death. It was only a perception and has not been medically researched to conclusion. Only when she started complaining about a stranger in our house and when I realised that the stranger was me, I decided to seek medical advice.

First I took her to our Family Doctor, living down the same road. His treatment did not do anything good to her. Thereafter, I took her to another doctor. He too could not diagnosis the real cause for her changed behaviour. Finally, I took her to a Psychiatrist. His diagnosis was a 'possible multiple infract dementia, that is, Dementia caused by many little strokes'. I think his diagnosis came closer to the final one. His medication also gave some kind of relief to my mother.

When I told my sister about the latest consultation and his diagnosis, she told me that in Australia, where she is living now, this type of disease is very common and according to information she had collected, my mother's problem was not a Psychiatric one, but something to do with her brain nervous system. She requested me to consult a Neuropsychologist.

As I could not find a Neuropsychologist in Sri Lanka, I was told to consult a Neurologist. On his request, an MRI scan of the Brain was done.

He also carried out extensive Psychological test of memory, general knowledge, thought processes, the capacity to name and the use of everyday objects.

He got some blood tests also done to eliminate other conditions that may mimic or resemble dementia condition.

Based on his study of the reports, he was of the opinion that my mother had Alzheimer's disease and in stage Two, the longest stage.

Unfortunately, as of now, there is no cure for Alzheimer's disease. Therefore, the medication recommended by him was to slow the progression of the disease from stage Two to Stage Three which is the final stage.

Three years have passed since she was diagnosed with stage Two of Alzheimer's disease and by now she may have reached the Final stage. However, we have been advised to continue with the same medication, until changes are recommended by him. That is why we are making these routine visits."

At this point, both Himi and Agil were taken aback having listened to Jothi, but in their own minds they thought, what they learnt from Jothi would help them if they were to encounter such a situation in their own family.

As they got up to leave, Jothi thanked them for the visit and requested them to have regular visits.

Himi and Agil agreed to Jothi's request and went closer to where Kala was seated and said:

“Goodbye Aunty, we will certainly come again to see you.”

There was no response from Kala but they noticed a smile in her face which reduced their sadness to some extent. They got into their car and just before leaving, asked Jothi whether they could help her in any way. A surprised Jothi said:

“Thank you very much; it was only two weeks ago, I met Himi and today you are offering to help me. That itself is a big gift from you. Thank you, once again.”

“As I said earlier there is no cure for my mother's disease. She has to live with it and we have to live with her. My sister is taking care of our financial needs. All that we need now are friends. Perhaps, new friends because all our old friends have deserted us when we most needed them. They think Alzheimer's disease is a disgrace. It is not, it is a disease like any other.”

Himi and Agil felt very sorry for the some what emotional Jothi and said:

“Don't worry Jothi we will be your new friends and we will be with you always.”

With that encouraging assurance, Jothi wished them Goodbye.

Three

Himi's family owned a tea estate in Deniyaya and an Administrative office in Colombo. Himi is the Chief Executive Officer and a working Director. Her father Ajith is the Executive Chairman of the Board of Directors and he is directly in charge of Managing the estate. Her mother Agil is a non-working Director. It is a family concern.

Himi's visit to Jothi and seeing her mother in that condition made some unexplained changes in her heart and mind. For a few days, she was not able to concentrate fully in her work. She was determined to do something for Jothi and her mother.

When she called Jothi the next time, she wanted to know from her whether she would accept a suitable job in her Colombo office. Jothi, highly appreciative of Himi's offer, thanked her and said she gave up a well paid job in order to be a full time care taker of her mother.

When Himi continued to express her desire to do something for Jothi's mother, Jothi remembered the help she received from the Lanka Alzheimer's Foundation when her mother was first diagnosed with Alzheimer's disease. The volunteers from this foundation visited them periodically and helped them to cope with difficult situations.

She spoke to Himi about their services and suggested that she support their work. That way, she will not only be helping Jothi's mother but also several others who are suffering from this disease.

It is estimated that there are over eighty thousand *people diagnosed with Alzheimer's disease in Sri Lanka. Himi gladly accepted Jothi's idea, got the contact details from her, and followed it up.

* In 2007

Four

When Jothi was planning for the next consultation visit to the Doctor, she received a call from Himi, inviting them to her residence either before or after the consultation with the Doctor. Jothi herself had been planning such a visit and gladly accepted Himi's invitation. A happy Himi offered to pick them up.

On the appointment day, Himi along with their family driver went to Jothi's apartment, picked both of them and the female helper and went straight to the hospital where the consultation was to take place. Although they arrived on time for the appointment, the Doctor was late by an hour and Jothi said it was not something unusual. When Kala's name was called, Himi said, she was interested in watching the consultation with the Doctor and therefore, both of them took Kala to the doctor's room.

The Doctor knew the condition of his patient and he had only a few questions to Kala, one of which was whether she knew who he was and Kala said something about raining outside. The rest of his questions were to Jothi. It was about Kala's behaviour changes since he saw her last, about her response to medication, her eating and her sleep at nights. Jothi with a small note book in her hand answered all the questions.

The consultation lasted for about fifteen minutes and at the end the Doctor updated the prescription. He told Jothi to see him after three months and it was not necessary to bring her mother when she comes for future consultations unless she had some serious problem. The Doctor also gave her his new mobile number to contact him in case of any emergency.

As they came out of the Doctor's room, Himi wanted to know from Jothi whether she has anything else to be done. On being told that she only wanted to visit her residence and get back to their apartment as soon as possible because her mother was already tired and exhausted. Himi realising the situation took them straight to her residence at Ward Place. They were warmly welcomed by Himi's father Ajith and mother Agil. After the introduction, a review of what took place since Himi's first meeting with Jothi and Kala followed.

Ajith insisted that they spend the rest of the day with them. On being told of their difficulty in staying for long hours, Ajith requested, at least to have lunch with them. Finally they agreed to settle for a quick snack.

Jothi glanced through the beautiful house, which was elegantly furnished. What impressed her most was not the house or the furniture but the simplicity of Ajith, Agil and Himi.

Despite having a family driver, Himi was driving the car herself with the driver seated next to her. Despite having a gardener in the house, Ajith was seen watering the garden when they arrived. Despite having a cook in the house, Agil was preparing the tea for them. Despite having a second servant in the house, Agil and Himi were serving the snacks. Jothi in her mind compared these people with some others whom she knew and thought to herself, that different people live differently.

When the time came to leave, everyone was sad and Jothi, usually being emotional, had tears in her eyes. It was in a way to thank them for the love and affection shown in her.

Himi drove them back this time without the driver, because she wanted to drop in at her office to attend to some work after leaving Jothi and them at their apartment.

Five

Himi and Jothi continued to be in touch with each other over the telephone and Himi made it a point to visit Jothi's apartment at least once a week, some times alone and at times with her mother.

In the present context, this new friendship was unique and it was the talking point of Jothi's neighbours, friends and relatives. It also brought about some positive development in that neighbours, friends and relatives who kept away from Jothi, had started getting closer to her again. One or two neighbours even offered their vehicles to transport her mother to the hospital for the next consultation with the Doctor.

Three months later one day when Himi telephoned Jothi, they had to talk about Kala's difficulty in communicating with others. From then onwards, it was problems, one after another in Kala's mobility, hearing and vision. For all these the Doctor's response was that, it was part of progressive deterioration.

He had told Jothi that with Alzheimer's disease being what it is, she had to accept this process and be prepared to cope with it with the help of medical personnel and others close to her family.

Six

Jothi kept her sister informed of all these developments, which made her advance their planned visit to Sri Lanka. As soon as Avanthi and Hari arrived in Sri Lanka, they had a special consultation with Kala's Doctor. They were able to obtain a report from him with regard to Kala's condition for submission to the Australian High Commission to obtain special Visas for Kala and Jothi to travel to Australia.

At the first meeting with the officials at the High Commission, they were requested to make the formal application for Visa with a special undertaking that Kala will be admitted to a suitable Care Home for Alzheimer's sufferers in Australia at no financial cost to the Australian Government. Also on condition, that Jothi's stay in Australia will be for a limited period.

The Visa applications were submitted together with the required undertakings and they were told that it would take at least six weeks for them to get the approval from the Australian Government

Avanthi and Hari were confident that they will succeed in their endeavor and proceeded with other arrangements to facilitate Kala's and Jothi's travel to Australia as soon as the Visas were approved.

Seven

When they returned to Australia, they discussed their plan with their friends and tentatively made reservation in an 'Alzheimer's Care Home' to admit Kala as soon as she arrived in Australia.

Six weeks later, the Australian High Commission in Sri Lanka informed Kala and Jothi that their application for Visa has been approved. They were requested to call over at the High Commission with their Passports and collect their Visas. Kala was issued with a Resident Visa but Jothi was issued only a Visit Visa valid for six months.

The first person Jothi contacted after collecting the Visa was Himi with whom she has been in touch regarding the Visa matter.

Himi expressed happiness over the news and promised to see her before they leave for Australia. Avanthi, on receipt of the news made final arrangements for Kala and Jothi to fly into Australia.

On the day of the flight, the first to arrive at their apartment was Himi, Agil and Ajith.

Jothi introduced them to her friends and relatives who came there to see them off to Australia. It was a happy moment for everyone and Jothi spent an hour with them.

The sad part of all these was the fact that Kala did not understand what was going on in her apartment. She was not even in a position to find out from anyone because of her difficulties in communication. Realising that their stay longer may disturb Jothi's arrangements for the flight, they got up, wished them a pleasant and safe journey and before leaving handed over a parcel of freshly packed Tea from their estate to Jothi to be taken with them to Australia. Jothi thanked them for the tea and in return handed them a basket of mangoes received that morning from a friend in Jaffna.

An elderly person who was present there recollected how in his younger days in Colombo, he had witnessed such exchanges of gifts more frequently and wished that it continued in the future. As soon as Himi and her parents left, Jothi told all those present there that if there is anyone whom she will never forget in her life time, it was Himi, the girl who just left. This remark of Jothi caused little embarrassment to some but they all accepted her feelings towards someone who really helped her when all others isolated them.

When it was time for them to leave to the Airport, Jothi thanked her female helper and told her that she will be back in six months time and that she will contact her on her return. She also thanked all others present there. A neighbour and a friend who were present

there volunteered to join them up to the Airport. Jothi readily accepted their offer.

The flight took off on time and the two who went with them to the Airport returned home with the satisfaction that they were able to do at least some help to Jothi who underwent immense difficulty in caring for her mother alone for a long period of time.

Eight

On arrival at the Sydney Airport in Australia, they were received by **Avanthi**, Hari and their little son Sanjeev. A few of their friends were also present at the Airport.

After the Airport formalities were over, they went straight to **Avanthi's** house. They decided not to admit Kala to the **Care Home** immediately but a week later.

During the period Kala was in **Avanthi's** house, she did not realise that she was now in a different country. Even **Avanthi's** presence there made no difference to her.

Jothi soon got used to the new environment and was ready to **face** the changes. At the beginning of the second week, **Avanthi** contacted the Care Home where reservation was made earlier and requested for an appointment to admit Kala. As soon as they received confirmation of the appointment, they took Kala and admitted her.

The authorities at the care Home informed them that from then on, they will be responsible to the patient and that two nominees of Avanthi could visit the patient during specified hours.

An agreement was signed between Avanthi and the Care Home to settle their monthly bills on or before the tenth of the following month. Avanthi nominated herself and Jothi as visitors to Kala.

All those who went to admit Kala remained in the Care Home till late in the evening and found it was a wonderful place, where patients were truly loved and cared. With that happy realisation, they all returned home.

The following day both Avanthi and Jothi went to the Care Home to see their mother. They went closer to her and asked her whether she was comfortable at the new home. There was no response from her. However, they found that she was more relaxed and some what enjoying the new environment. Every time they said something to her, she only responded with a smile.

From then onwards, it was either Avanthi or Jothi who took turns to visit their mother.

Nine

At the end of the first month in Australia, Jothi had lot of time on her hands and was toying with the idea of doing a part time job during the remaining five months of her stay in Australia. When she sounded this idea to Avanthi and Hari, Avanthi readily agreed but Hari had some reservation about Jothi's Visa conditions. He was worried that her getting in to employment may lead to her visa being cancelled and sent back to Sri Lanka immediately. They decided, therefore to get some legal advice on the matter. They were advised that doing part time jobs without entering into any legal contract might be a way out for the problem. A 'Hire and Fire' system is already in place to avoid claim for compensation and terminal benefits. Jothi's idea was to keep herself occupied during the next five months without any consideration for compensation. She therefore, decided to respond to an advertisement by an outsourcing IT company for the Post of Support Officer on assignment basis for a period of three months.

Jothi has a Degree in IT and two years of working experience in the IT industry in Sri Lanka. She therefore, had no difficulty in facing the interview and got selected for the post. The appointment was from August first.

On the first day, she was directed to her 'Reporting Officer' Kailash Sivapalan, a Sri Lankan Tamil now a citizen of Australia, living with his parents in Sydney. Kailash has seen Jothika Vadivel's personal file before she entered his cabin. Therefore, he did not waste any time asking her about personal details. As soon as she entered his cabin, Kailash introduced him as her Reporting Officer of her assignment and spoke to her briefly about it. He then handed over a file to her and took her to the unit from where she has to work.

At the end of first month, she had completed more than one third of the assigned work, which covered the most difficult part. Jothi's simple ways and her positive approach to work drew the attention of not only her superiors but also her colleagues. Kailash was no exception.

Ten

Kailash was not married and his parents had been advising him to get married and settle down in life so that they could return to Sri Lanka and live with their other children. Kailash had been telling them to wait until he found a suitable girl to marry.

One evening after returning from work, while having tea, he started talking about Jothi to his parents and they realised that he was interested in her. They asked him whether he would like to get married to her. He said:

"I will have to find out from her whether she would like to get married to me."

Two days later, during the weekend there was a function in their office where a farewell was organized by the senior officers to a colleague who was being sent to another of their office with a promotion. All the staff, including Jothi was invited.

By the time Kailash arrived, Jothi was already there talking to others present at the function. Kailash noticed a vacant seat next to Jothi and quietly went and sat down.

Jothi was feeling little uncomfortable sitting next to her Reporting Officer and Kailash realising it comforted her and said that he has been living alone in Australia from his student days and his parents joined him only recently. He said his parents wanted him to get married and settle down in Australia so that they could return to Sri Lanka as soon as possible. He has been telling them to wait till he found a suitable girl to marry. Jothi was thinking to herself as to why Kailash should say such things to her. The answer came suddenly. He said:

“I have now found that girl in you.” and asked her whether she would like to get married to him. Jothi had a similar experience while working in Sri Lanka which gave her the courage to say:

“How can you propose to me without knowing fully about me and why I am in Australia? If you know that, you may run away from here.”

Kailash responded calmly:

“I like you and I want to get married to you. I will not under any circumstances change from this position. Now, please tell me about you.”

Jothi started with her family origin, about her Father’s death, her Mother’s Alzheimer’s condition, her dependency on her sister’s family living in Sydney and finally about the six months Visa. Kailash listened intently to her story and asked:

“What is that which will make me run away from here?”

A surprised Jothi asked:

“Why, all these are not enough for you to run?”

Kailash laughed and said:

“On the contrary, your story has only made me like you more. I have observed your positive approach to your work. Please see that you have a similar approach to your personal life which will help you in the long run.”

Jothi needed more time to respond to him, but without saying that she told him:

“Although I am an independent person, in the absence of my father and in my mother’s present condition, I need to be guided by my sister and brother-in-law. Perhaps, you may also need to consult your parents on this matter. I would therefore, suggest that you discuss with them and request them to meet my sister and brother-in-law.”

Kailash agreed, excused himself, walked towards the other officers, spoke to them for a few minutes and went away.

Jothi was a little confused but decided not to let her sister know about it until Kailash made the next move, but she needed to talk to someone to get it off her chest. The person who came to her mind was Himi. She had earlier spoken to her, once after admitting her mother in the Care Home and later when she got the job. Himi's telephone rang and the Caller line identification indicated "Unknown Number" she realised it was an overseas call but could not guess the caller. She was very happy when she heard Jothi's voice over the phone. She wondered whether she was going to give her some good news or bad news and said:

"Yes, Jothi what is the latest....." Jothi replied:

"Everything has gone well until today."

Himi interrupted her and asked,

"Why, what has gone wrong today?"

Jothi repeated her encounter with Kailash, which Himi listened attentively and finally said:

"Jothi, I think that boy is genuinely in love with you."

and joked,

"Why, if I was a boy, I would have fallen in love with you, the first time I met you. So I am not surprised that he has fallen for you. So consider his proposal seriously and everything will work well for you."

Jothi wanted her regards conveyed to Agil and Ajith. Himi said, she would do that and asked her about Kala's condition and said she was still in touch with the Alzheimer's Foundation and looking forward to participate in their 'Memory Walk' held annually in September to celebrate world Alzheimer's Day. After the telephone conversation with Himi, she felt somewhat relieved and waited for Kailash's next move.

Kailash with a clear mind went home and told his parents about his meeting with Jothi. They discussed the matter till late in the night and Kailash identified only a single problem. It was Jothi's six months visa and only four months left. Something has to be done within the next four months and being a positive thinker, he thought to himself that it could be done. At this point, his mother came out with another problem. It was Jothi's mother's Alzheimer's condition. She said:

"After arriving in Australia, I have watched a health program in the Television in which the Alzheimer's disease was discussed. According to my understanding the disease runs in the family."

Kailash's father tended to agree with his wife, but being more liberal in his thinking said:

"It may be one in a thousand and Jothi may not be the one in any thousands. It could affect anyone, including you and me." and jokingly asked,

“If you get it, do I throw you out or if I get it, will you throw me out? If we look at these things narrowly, Kailash may have to remain a bachelor throughout his life.”

Kailash in order to convince her mother that the disease does not run in all families, started a search on websites and found, that while Alzheimer’s disease does run in families, it is not passed on from one parent to their children in general population, but only when a number of family members are affected and the disease has started at a relatively young age. Satisfied with that finding, they all decided to meet Jothi’s family as early as possible

On the first working day after the weekend function both Kailash and Jothi reported to work as usual. There was no excitement in their behaviour during the day. It was when they were about to close office for the day, Kailash sent a word to Jothi to see him before she left office. The message appeared official and she also responded in the same manner.

As soon as she entered his cabin, Kailash said:

“I have spoken to my parents and they are willing to meet your sister and brother-in-law. I want to tell you that I am not compelling you in anyway.

You are free to speak your mind to your people and only if all of you agree to my proposal, that I shall send my parents to meet them.”

Jothi appreciated his approach and began to like him. She therefore said:

“I shall speak to them and get their approval for your proposal” and left the place.”

Jothi on her way home went to see her mother at the care home, because it was her turn to visit her. She was sad, she could not share with her what was in her mind. Yet, she went closer to her and said:

“Your Jothi is going to get married soon.”

Kala’s response, as usual was only that faint smile. Jothi also spoke to the caregivers and thanked them for the way they were caring for her mother.

When she returned home, Avanthi and Hari were still at work. She had a few words with Sanjeev about his studies and started preparing dinner.

At dinner time, Jothi was unusually quiet and was deep in her thoughts. That was the first time Avanthi saw her in that mood and asked her whether anything had gone wrong.

After a pause Jothi said:

“No – nothing went wrong; but I want to talk to you and “Atthan” about what happened yesterday at the farewell function and today in office, I need your advice.”

Before, Avanthi and Hari could ask anything, Jothi proceeded to explain the encounter with Kailash at the farewell function and what followed in office that day. At this point, Avanthi asked her whether she liked Kailash. Jothi replied that she seemed to like him after he spoke to her. Hari, after listening to their conversation asked Jothi:

“If you like him, what is the advice we could give you on this matter.”

Jothi replied:

“Well, I have lost my father, my mother is silent and will not be able to participate in any decision making. Therefore, I am depending on you and Acca to guide me to my future.”

Hari agreed with Jothi’s position and said:

“I myself have been thinking in terms of giving you in marriage to someone with Australian citizenship so that you could continue to stay close to your mother in Australia.

If Kailash has Australian citizenship and if he is proposing it to you, I think you should consider it; but before that we must meet them and clarify certain matters.”

At this point, Jothi reminded them of what Kailash told her and that is, only if all of us agree to accept his proposal, that he will get his parents to meet us to discuss this matter.

Hari said:

“If you like him, it is like accepting his proposal and we have no problem with that; so let us meet them during this weekend.”

Avanthi also agreed with all that was said by Jothi and Hari. She has in fact, started praying that this proposal should go through and make a bright future for Jothi; for she know more than anybody else, the difficulties and sacrifices of Jothi in caring for her mother when they were in Sri Lanka. Jothi was happy with the new development and hoped to convey it to Kailash when he gave her that opportunity.

The next day both Kailash and Jothi were at work and their new relationship did not in anyway disturb their work. That was the initial sign that they could be a model couple in the future. Like the previous day, Kailash after completing his work for the day, sent word to Jothi to see him before she left office. A little later, when she entered Kailash’s cabin, he asked her whether she has any good or bad news for him.

Jothi, in a jovial mood said:

“I have good news for you, my team is ready to meet yours during this weekend to begin the new game.”

Kailash was so happy with that news, got up from his seat and said:

“Thank you very much Jothi; I will send my team to play the game to the final”and sat down.”

Jothi welcomed his acknowledgement, went to her unit, arranged her table and left office for the day.

It was not Jothi’s turn to visit her mother at the care home, but she decided to go there and tell her mother about the latest development. She knew that her mother will not understand these things but she still wanted to share her happiness with her.

Avanthi was not present when she arrived and that suited her to go near her mother took her hand and whispered in her ears:

“Your Jothi’s marriage is getting shaped up.”

she did not expect any response from her mother except the usual smile. Just then Avanthi arrived and she was somewhat surprised to see Jothi with her mother. She asked her whether she came to give the good news to Amma. Jothi’s response too was a smile; but she said she has told Kailash about their decision to meet his parents during the weekend.

Avanthi and Jothi after reaching home and while preparing dinner were discussing the arrangements for the visit of Kailash’s parents. Jothi was of the view that in the absence of her mother, any arrangement made must be as simple as possible. Avanthi disagreed stating that they may misunderstand them. Jothi said, she could explain matters to Kailash prior to their arrival.

Avanthi wanted Hari’s opinion also on that matter and when they took the problem to him, he said, if they took them out to some place for dinner to talk things over, they could avoid making any arrangements at home. Everyone agreed with it and wanted Jothi to convey that to Kailash.

The following day when Jothi went to Kailash’s cabin for some official matter, she took the opportunity to inform Kailash about their decision to take his parents out for dinner during the weekend. Kailash had no problem with that and said that he will drop them at the nominated place and suggested to Jothi to keep out of their first meeting. Jothi also wanted it that way and had no difficulty in agreeing with his request.

Eleven

The meeting took place between the two parties in a wayside restaurant where meals of all tastes were freshly cooked and served. Kailash's father Sivapalan was a retired principal of a school in Jaffna. His wife Devarani was also a retired teacher. When they were talking about their teaching days, Hari said, his father Krishnakumar was also a mathematics teacher married to his cousin Lalitha, a house wife.

At this point, Sivapalan remembered the name Krishnakumar and asked for more details about him from Hari. He found that both of them had taught together in a school in Kandy, when they were young. He also remembered that Krishnakumar had a son and inquired whether it was him. Hari said, it was his elder brother Kanthan, died in an accident a few years ago. Hari was born after his father was transferred to a school in Colombo. Hari further explained that he, like his father, married his cousin Avanthi. That is, Avanthi's mother Kala is Hari's father Krishnakumar's sister. Since Sivapalan was aware of Krishnakumar's family background,

it made easy for him to know the family background of Jothi as well.

Hari wanted to know from Sivapalan, Kailash's status in Australia and whether his marriage to Jothi will permit her stay in Australia permanently. He said it was their primary concern. Sivapalan explained that Kailash has been living in Australia for more than ten years. He is now a citizen of Australia. He will attend to all legal formalities to marry Jothi before her visa expired. After that she could apply for her continued stay in Australia under the family reunion category.

The other matter Hari took up with them was about Kala's Alzheimer's condition and her present stay in a care home. Sivapalan said they were aware of it. Hari said the present arrangement is for Avanthi and Jothi to visit their mother in the care home in turn and wanted to know whether they will have any objection to continue with the present arrangement.

Sivapalan said, these are part of everyone's life today and there should be no objection to it from anybody.

“As you know we won't be here for long, but we are sure that Kailash will certainly support Jothi in this matter.”

At this point, Devarani wanted to know whether they could visit the care home to see Kala. Avanthi said, only she and Jothi are nominated visitors and they could go there only with any one of them. Hari intervened and said, let Jothi take them one day when she is visiting her mother.

Sivapalan and Devarani were happy with that suggestion, because it gave them an opportunity to meet Jothi.

Hari inquired from Sivapalan whether they have any thing to be clarified. Sivapalan said, they need no clarification; but only wish to convey a request from Kailash. He said:

“To our knowledge, the only love affair Kailash had, was with his work and we were surprised when he came and told us that he was interested in Jothi and wanted to ask her whether she would like to get married to him.”

“He is mature enough to understand what is good for him and what is bad for him. Therefore, we have no problem with his decision. His request is to have the marriage ‘his way’ and that is, after the legal formalities is completed with regard to marrying a visit visa holder, to have a simple wedding ceremony in a Hindu temple in Sydney with only the family members in attendance and have the marriage registered in the appropriate office. Thereafter, to apply for the extension of Jothi’s visa, followed by an appeal for permanent stay under the Family reunion category. According to Kailash’s lawyers, the whole process will take about six weeks from now. After that, Kailash and Jothi will announce their marriage to the public and invite their friends and relations for a reception”.

Hari informed Sivapalan that they have no reason to disagree with that plan provided all these things are done in accordance with the prevailing law.

Sivapalan explained that one of his nephews, Ananthanadesan, earlier worked in the Attorney General’s Department in Sri Lanka, is now a legal consultant attached to the Ministry of Immigration in Australia. Kailash has already consulted him on this matter and he will follow his advice. Hari and Avanthi were satisfied with that arrangement.

As the meeting concluded with the dinner, Sivapalan used Hari’s mobile phone to inform Kailash of the outcome and told him to pick them up from the restaurant. Within minutes, Kailash was there and he was formally introduced to Hari and Avanthi by Sivapalan.

On their way home, Hari and Avanthi realised the reason for Jothi to say that she liked Kailash after he spoke to her. He was very smart, well mannered in his speech and action and a ‘God sent Gift’ for Jothi was the opinion of Hari and Avanthi, after their short meeting with him at the restaurant.

When they arrived home, Jothi was not excited and she continued to help Sanjeev with his studies. It was Avanthi who broke the ice and said:

“Jothi you are very lucky. Amma would have been very happy if she is able to understand what was going on here. Anyway, we must go and give her this good news.”

At this point, Jothi, like her mother only smiled, but Kailash’s earlier assertion that he liked her and that he wanted to get married to her and that he will not under any circumstances change from that position gave her enough confidence in him and the courage to stay cool.

Jothi had earlier told Himi about the weekend meeting and promised to call her after the meeting took place. It was 10.30 a.m. Sunday in Sydney. She checked the time difference and found it was 6 a.m. in Sri Lanka. She thought it was too early to disturb Himi with a telephone call and decided to send an SMS reading,

“Hi – Himi successful meeting will call you later- Jothi.”

Himi was up and as soon as she received the message, she called Jothi. At the first ring Jothi guessed, it could be Himi and it was Himi who spoke:

“Hello lover girl, how do you feel.”

Jothi surprised with that opening remark said:

“I feel fine, thank you for the call; I have still not been attacked by the love virus. It is only the beginning of an understanding; an understanding between two people; Just like the understanding between you and me. My heart is full of my mother and it will take sometime for me to adjust.”

Himi understood her feelings and said:

“Jothi, I understand your feelings for your mother, particularly when she is in her present condition; but you have a heart big enough to accommodate both your mother and Kailash; I am sure that Kailash has an equally large heart to care for you and your mother.”

Jothi appreciated very much Himi’s mature advice, and thanked her for it. The call ended with the pledge to be in touch with each other.

The happenings during the weekend did not in anyway affect the performances of Kailash and Jothi at their work on Monday. Without consulting each other, they on their own decided to maintain the status quo. For them and others in their office, their relationship, continued to be that of Jothi being a ‘support staff’ working with her Reporting Officer Kailash.

Days and weeks passed by and at the end of the second month Jothi had almost completed her assignment. What was left to be done were the review by her Reporting Officer and the approval by the company’s Chief Executive Officer – CEO which normally takes about three to four weeks.

Kailash has been attending to all the legal formalities in consultation with his uncle Ananthan, and reporting the progress to Hari and Avanthi through Sivapalan. Avanthi in turn kept Jothi updated with all the information they received.

The day before Jothi’s Assignment ended, the CEO of the Company called Kailash and Jothi to his cabin and told them that he has approved the project worked out by them and wanted to know from Jothi whether she will undertake another assignment. Kailash did not allow her to respond to the request of the CEO, but intervened and said:

“Sir I have already spoken to Jothika about it and it appears that she has some personal difficulty in taking up another assignment immediately.”

Since he used the term ‘personal difficulty’, the CEO did not persuade her further and said:

“Alright then, thank you very much for the excellent job done and wish you all the best.”

They came out together and she did not take any objection to his talking on her behalf because, she already believed that anything said or done by him was for her good.

On the last day of her assignment, Jothi reported to work as usual, cleared her table, handed over the files to those in charge, spoke to her colleagues one by one, collected her pay cheque from the Accounting Officer, met the Reporting Officer and finally met the CEO, thanked him, and wished him Goodbye. She left office along with others at the closing time. Coincidentally, it was her Mother’s Birthday.

She went to a flower shop, bought a basket of flowers and went to see her mother at the care home. From the records the caregivers knew, it was Kala’s Birthday and they kept her nicely dressed when Jothi arrived to wish her mother a “Happy Birthday”.

A little later, Avanthi also came there with a Birthday cake. All of them got Kala to cut the cake, sang the Birthday Song and fed her with a piece of cake.

Avanthi and Jothi took a piece each and gave the rest to the caregivers and told them to share it with the other patients in the same unit.

Avanthi and Jothi remained with their mother for sometime and when they were ready to leave, they saw Sivapalan, Devarani and Kailash walking towards them. Although the earlier understanding was for Jothi to take Sivapalan and Devarani to see her mother during one of her visits, Kailash did not like the idea on the basis that it should happen only after Jothi completed her assignment with the company. When Kailash decided to take his parents to the care home that day, he had hoped that either Avanthi or Jothi will be there, otherwise they would have had some difficulty in entry to the care home. None of them knew that it was Kala’s Birthday and they were very happy that it was on her Birthday, they visited her. When all these things were happening, Kala, like a little girl, was watching them without any expression in her face, except for that little smile. Sivapalan and Devarani met Jothi for the first time, had a word or two with her and were very happy with Kailash’s choice of his bride.

When Avanthi and Jothi went home, Hari was already there helping Sanjeev with his home work. At dinner time, they spoke of the day’s happening including their visit to the care home to wish their mother on her Birth day and the visit of Sivapalans to the care home.

At the end of the fourth month, Jothi knew the road map of Kailash, but without a job in her hand she found it difficult to plan out her day to day activities.

She had plenty of free time, most of it she spent with her mother at the care home. She had no direct contact with Kailash and had to depend on Avanthi to update her with the latest from him.

It was at the end of the fifth month, Avanthi came with the news that Kailash has got the approval to marry Jothi, a person with a 'visit visa' to Australia.

In terms of the Hindu tradition it is the responsibility of the Bride's party to make all arrangements for the wedding. Hari used to visit the nearby Hindu temple and was friendly with the chief priest. After discussing with Sivapalan, he made arrangements with the priest to have the wedding at 10 a.m. on December 13. Jothi's only request was to have her mother present at the wedding. Accordingly, arrangements were made with the authorities of the care home to bring Kala to the temple at 10 a.m. and keep her there for about an hour.

All others present at the wedding were close family members of both Kailash and Jothi. Immediately after the wedding, the couple along with two others went to the office of the Area Registrar of Marriages and got their marriage registered. At the invitation of Hari and Avanthi, all those present at the wedding proceeded to their home to join the couple at lunch. Later in the evening, they all accepted Sivapalan's invitation for dinner at their home. The dinner formalities lasted until 9.30 p.m.

Kailash was supervising a project in office, which was required to be completed before Christmas holidays.

Therefore, he took only a day's leave for his wedding and did not even inform his office about it. Before leaving for office next day, he sat with Jothi and prepared her application for the extension of her visa, which was to expire on December 20. The reason given for the extension was her intention to apply for permanent stay in Australia consequent to her marriage to Kailash, a citizen of Australia on December 13. Her application with the certificate of Marriage was handed over to his uncle Ananthan. Jothi did not take issue with Kailash on his one day leave for his wedding for two reasons. First being, she fully understood Kailash on these matters and the second being, her unpreparedness to start enjoying her married life. Everything happened unexpectedly and so sudden, it was like a dream for her. She needed more time to change her attitude towards her personal life.

Jothi spent the whole day with Sivapalan and Devarani, most of the time answering their questions and other times remaining silent. Sivapalan and Devarani understood her loneliness and were awaiting the return of Kailash from his office to take her out for a drive.

Jothi wanted to visit her mother but was reluctant to suggest to Sivapalan and Devarani. Just then Kailash arrived and on seeing Jothi with his parents said:

"Jothi you must keep your turn to visit your mother at the care home and for a start let us all go and see her today."

This is the kind of thinking that Jothi appreciated in Kailash and readily agreed with a smile.

The thinking of Sivapalan and Devarani was different, in that they wanted the two left alone. Sivapalan said:

“A very good idea, let both of you go today we shall make it some other time with Jothi.”

Kailash and Jothi got the intended message and accepted their suggestion without any dispute. In order to give them more time alone, Devarani suggested they should eat at the nearby ‘Night Cafe’ and bring some dinner for Sivapalan and her when they return.

The visit of Kailash and Jothi did not make any difference to Kala. For her, they were just two other inmates of the care home. Jothi’s visit to her mother was only to see the little smile on the face which she saw even on that day. Jothi introduced Kailash to the two caregivers of Kala, spoke to them for some time and left the place.

While at dinner at the ‘Night Cafe’ Kailash told Jothi, he was planning a trip to Sri Lanka after the wedding reception in January. His CEO had called for a report from him on the feasibility of establishing an outsourcing IT Centre in the Northern part of Sri Lanka. He needs to talk to people who are interested in the IT industry or would be interested in getting into the industry. Also he had not visited Sri Lanka for ten years and hoped to meet some of his old friends and relatives during the two weeks stay there. He invited Jothi also to join him so that they could have the second honeymoon in Sri Lanka.

She smiled and said, she likes the idea of going to Sri Lanka, but before that they need to decide about the apartment she owned in Colombo. Kailash asked her whether there was any problem with it. Jothi said:

“It is not a problem as such; it was gifted to me by my father before his death. Our original house in which all of us lived was gifted to Avanthi when she married Hari. She sold it before they came to Australia. When I got the six months visa, I arranged with one of my aunts to look after it till I return to Sri Lanka. Now the situation has changed. In fact, when my aunt got to know that I am going to be married and settle down in Australia, she offered to buy it at a reasonable price. We need to decide whether we are going to sell it or not.”

Kailash suggested that she should discuss this issue with Hari and Avanthi and decide on it. Jothi said, she could get their advice on the matter but the decision to sell has to be made by them meaning Kailash and Jothi.

Kailash did not understand Jothi’s logic and asked for clarification.

Jothi said, before she married him, she was the sole owner of the Colombo apartment, but with her marriage to him, he becomes a co-owner.

Kailash laughed with her and said any decision taken by her will be acceptable to him. That settled the matter for the time being.

After they finished their dinner, they walked over to the 'take away' counter, picked up some food, favoured by Sivapalan and Devarani and returned home a little late in the night.

On December 20, seven days after the wedding, when the telephone rang, Sivapalan was resting in his bedroom, Devarani was having a late lunch, and Jothi reading the day's newspaper answered the phone. The caller asked whether it was Jothi and when told, it was her, he introduced him as uncle Ananthan and told her that her visa had been extended for another month. Her appeal for permanent stay in Australia must be made forthwith. Jothi wanted that information given to Kailash but uncle Ananthan said, he has already informed him and in fact, it was he who wanted the news passed on to her.

After Kailash returned from work, the whole family gathered in their sitting room and were looking back at events one after another leading up to the extension of Jothi's visa. Sivapalan expressed happiness over everything but regretted that no other family members were present at Kailash's wedding.

He asked Kailash, whether it is possible to get down at least his elder sister and younger brother from Sri Lanka for the wedding reception. Kailash appreciating his father's concern said, it may not be possible, because he was planning to have the reception within the next three weeks and getting visa for them will take at least six weeks. He also said, he was planning an official trip to Sri Lanka in late January after the reception and have requested Jothi to join him, so that they could meet all their relatives.

Sivapalan said, in that case they will also join them and stay back in Sri Lanka. Kailash did not agree with that, and said, someone would have to be there when they were going to be out for about two weeks. He promised that on their return from Sri Lanka, he will make the necessary arrangements for them to return to Sri Lanka.

On December 21, Kailash handed over Jothi's appeal for permanent stay in Australia to his uncle for lodging with the immigration appeal board. The appeal was made mainly on the following:

1. That Jothika's mother Kaladevi is an Alzheimer's patient. She was diagnosed with this disease five years ago when she was in Sri Lanka. Jothika has been caring for her mother from the beginning and has been always with her, even giving up a lucrative job. Special permission was granted to Kaladevi with the permanent visa to travel to Australia for admission in an Alzheimer's care home. Jothika who is familiar with Kaladevi's personal disabilities accompanied her. She need to be always with her to guide the caregivers, was granted only a visit visa for six months. This has just been extended for another month. With Jothika's father's demise and mother being in a care home in Australia, she has no other close member of her family in Sri Lanka to live with even for a short period. Jothika loved her mother very much and wants to be with her during her last days of life.

2. That on December 13, with special permission she married Kailash Sivapalan, a legal citizen of Australia. Being newly married, she would like to continue living with him in Australia.

When making this appeal, they were advised that even if it was rejected on the first count, she will succeed on the second. However, in allowing the appeal on the second count, they may request her to return to Sri Lanka and follow the set procedure in applying for a Family reunion Visa that may take anything between four to six weeks. That she has no other close members of her family in Sri Lanka to live with even for a short period was included in her appeal to avoid such a situation.

Jothi continued to update Himi with the happenings in her new home. During her last telephone conversation, she spoke of the possible trip to Sri Lanka with Kailash in January. Himi was delighted with the news and invited them to be their guests when in Sri Lanka. As Jothi was not aware of the arrangements Kailash would be making, she promised to confirm it after discussing with him. With plenty of time on her hands, she visited her mother almost daily.

With six months stay in the Care home, she did not notice any improvement in her condition; but she was happy that she did not get worse.

On January 4, two weeks after Jothi's appeal, when she opened their mail box, a letter addressed to her from the Immigration appeal Board was found.

The Secretary of the Appeal Board has requested both Jothi and Kailash to call over at their office for an inquiry on any working day between the morning hours 10 a.m. to 12 noon or afternoon hours 2 p.m. to 4 p.m. Prior confirmation of their convenient date and time with the Secretary was necessary.

Since Kailash preferred an afternoon appointment, he told Jothi to confirm for 2 p.m. on January 5. When Jothi called the Secretary, she was told that the appointment for 2 p.m. has already been booked and offered the appointment at 2.30 p.m., the same day. Jothi accepted it and Kailash was duly informed.

On January 5, they arrived five minutes to 2.30 p.m. and reported to the Secretary. She ushered them to a room and requested them to wait there until the arrival of one of the inquiring officers. Sharp at 2.30 p.m. a lady with a folder in hand walked in and said:

“Good afternoon Jothika Kailash and Kailash Sivapalan, I am Iris Johnson. I must apologise for not giving you the appointment at 2 p.m. as requested by you.”

Jothika replied:

“We have no problem with that; in fact, we must thank you for granting the appointment at 2.30 p.m. the same day.”

Iris Johnson said:

“You are welcome.” and glanced through the documents in the folder.

She asked Jothi about her educational and professional qualifications. She also asked her whether she intend looking for a job in Australia. Jothika gave particulars of her qualifications and said she will not be looking for a job immediately,

“Not as long as my mother is in this condition.”

Iris Johnson then asked about her other family members. Jothika said she has only a sister, Avanthika elder to her, married and presently living in Sydney with her husband and son. Iris Johnson then asked as to why she has not come forward to care for her mother.

“You say you want to stay in Australia to care for your mother. Why can't she who is already here do that?”

Jothi realised where she was leading her to and said:

“Not that she has not come forward to care for her mother, in fact, she is taking care of all our financial requirements. She is a working mother, a telecommunication Engineer by Profession with no fixed working hours.

The care home permit visits only during specified hours and very often she had missed her visits. Also, she had no experience in caring for an Alzheimer's patient. When my mother was diagnosed with this decease, my sister was not in Sri Lanka. It was I who cared for her during the last five years.”

Iris Johnson then turned to Kailash and asked him as to when and how he came to Australia, about his qualifications, his present job, income level and income tax payments. Kailash responded to all those questions and finally she asked him whether his family health insurance covered Kaladevi's disease. Kailash replied that his family health insurance covered only his parents and not his in-laws.

The inquiry lasted for about fifteen minutes. Iris Johnson made some notes in the folder, excused herself and walked towards another room which carried the name board 'Chairman.'

Ten minutes later, she returned with a smile and told Jothika that they have decided to allow her appeal. She said:

“In allowing your appeal, we have given careful consideration to your mother's Alzheimer's condition. Take care of her. Coincidentally, my mother is also a sufferer of this disease. She is ninety years old. She was seventy five when she was diagnosed with Alzheimer's disease. She is also in a care home, far away from here. I am not able to visit her as much as I would like to but I visit her at least once a month. On other days, I pray for her from home and thank God for keeping her alive.

At least I can see her whenever I go there even if I cannot communicate with her. Mother's love is great.”

She stopped for a moment wiped her tears and recited a poem:

“When all other love has vanished
When all other friendships fade
There is a love that moves behind us
In sunshine and shade
And that’s a Mother’s Love.”

Kailash saw Jothi in tears, comforted her, got up, thanked Iris Johnson for allowing the appeal and was about to leave when the Secretary came in and handed an envelope which contained the original documents that was attached to her appeal and a copy of the order of the Immigration Appeal Board.

The last item in Kailash’s agenda was the wedding reception and he requested his father to meet Hari and Avanthi and fix the date. Kailash preferred to have it during the first weekend after ‘Thai Pongal’ (A Tamil Hindu Festival). Sivapalan met them and after discussion agreed to have it on Sunday January 16. Kailash undertook to organize the function. Kailash and Jothi decided to invite only one hundred people for the reception. Eighty of their personal friends and relatives and twenty from Kailash’s office. They designed a two page invitation card. The first page announced their marriage on December 13, and the second page invited the people concerned for the reception on January 16.

The reception was well attended at which a variety of food was served. After the dinner, Hari made a short speech and thanked all those who attended the function and wished the couple a happy wedded life. Thereafter, one by one the guests wished the couple.

When the turn came for the CEO of the Company, where Kailash was working, to wish the couple, he after wishing them jokingly asked Kailash whether that was the personal difficulty Jothika had in not taking up the new assignment that was offered to her. Kailash did not say anything but only smiled which was like saying ‘Yes Sir.’

“Himi will also be married in January next year.”

“Why so long?” asked Kailash and said:

“Look at us, we took only six months.”

“That is true, but Himi needed more time to decide her future” said Ajith and explained that the boy is from a family known to them for a long time, studied Law in the States and presently practicing in partnership with an American. He has no intention of returning to Sri Lanka in the near future. Himi on the other hand was keen on staying in Sri Lanka and continue with her studies and work. We have seen the boy when he was very young and before he went to the States with his parents ten years ago. They are now living in Los Angeles. It was only after meeting him when he came to Sri Lanka last month to attend a family wedding with his parents that Himi gave the green light, but she wanted time to finalise her studies and her work in Sri Lanka. Therefore, all of us got together and decided on a date in January next year”. When all these things were being said, Himi was looking at Jothi and smiling.

When they reached the Colombo Hotel, it was dinner time and Kailash invited them to join them for dinner which they gladly accepted.

While at dinner, they were discussing various matters of common interest and when Ajith said, he has to run between their Colombo office and the Estate in Deniyaya to keep things in some order.

Twelve

Kailash discussed the Sri Lanka project with the CEO and got the office staff to make the necessary arrangements, including travel on January 23. He made separate arrangement for Jothi also to travel with him on the same flight. Since it was an official visit, he preferred to stay in a city hotel with secretarial facilities so that he could work on the Project from the hotel.

As soon as they got the ticket and the hotel accommodation confirmed, Jothi telephoned Himi and told her about the hotel arrangement and gave her the flight details. Himi regretted that Jothi and Kailash could not be their guests but she promised to be at the airport to receive them and bring them to the Colombo hotel.

On arrival at the Katunayake airport on January 24, they were received by Ajith, Agil and Himi. Jothi introduced them to Kailash and they all thought to themselves that Kailash was specially made for Jothi. They were extremely happy that Jothi married Kailash. On their way to Colombo, it was Agil who casually said:

Having listened to Ajith, Kailash said he may be able to develop a system which he could use on his computer to control the main activities from one point. All of them were pleased with the idea and requested that he work on it at leisure. Before leaving the hotel, Agil invited Jothi and Kailash for dinner the following night. They accepted the invitation with pleasure.

During the first seven days in Colombo, Kailash worked on the 'Sri Lankan Project' during morning hours and visited their friends and relatives in the evenings. They also met Jothi's aunt who was looking after their apartment at Wellawatte and accepted her offer to purchase it. They agreed to execute the legal documents before leaving Sri Lanka.

On the tenth day, they visited Jaffna, met the local representatives connected to the project and also visited probable sites for the project. In between, they also visited some of their relatives still living there.

On the thirteenth day, they returned to Colombo hotel, finalised their report on the project and kept the last day free to meet their friends and relatives at the Hotel before leaving Sri Lanka.

One thing Jothi wanted to do on the last day was to make a donation out of the sale proceeds of her apartment to the Lanka Alzheimer's Foundation, towards enhancing their services at the newly opened Centre in Colombo.

By prior appointment, they met the President and the Executive Trustee of the Foundation at the Centre and handed over a cheque to them, who in turn were very pleased with the gesture, thanked Jothi and Kailash and further requested them to promote the activities of the Foundation in Australia.

The next day, they took the first flight from Sri Lanka, spent a few hours in Singapore and took the connecting flight to Sydney.

On arrival at the airport, they were met by Sivapalan, Devarani, Hari, Avanthi and Sanjeev.

After two days of rest, Kailash reported to work and handed over his report on 'The Sri Lanka Project' to his CEO. The project report was subsequently approved and passed on to the unit which was in charge of implementing the project.

One week later, he made arrangements for Sivapalan and Devarani to return to Sri Lanka.

“Please do whatever is best for me that will relieve me of my loneliness.”

The next day, Kailash met his former Boss, the owner of an IT company whose operations were not in competition with his Company and handed over the Curriculum Vitae of Jothi. Looking at it, his former Boss had no hesitation in engaging her in a responsible position: Kailash informed his CEO about this arrangement in order to avoid any misunderstanding in the future. Jothi commenced work on the first working day in May and the life of Kailash and Jothi continued like any other Sri Lanka family in Australia.

Thirteen

At the end of March, Kailash and Jothi moved to a house closer to the care home so that Jothi could visit her mother more frequently.

Kailash, as usual, was busy with his work and Jothi, excepting for her visits to mother had difficulty in adjusting her life in the new situation. Kailash realising her unhappiness in staying alone at home without doing anything constructive asked her whether she would be interested in getting back to work.

A happy Jothi jumped at the idea and asked him whether it would not create any problem for him in his office.

Kailash said:

“I am not thinking of a job for you in our office. I may be able to arrange one in another office.”

What else Jothi could expect from his understanding husband. Jothi held his hands and said:

A Note From The Writer

PART- II

The names of all the characters in this work are the ones that came to my mind at the time of writing. It does not refer to any known or unknown person, dead or alive.

There is also reference to procedures with regard to:

- Obtaining special permission to admit Alzheimer's patients in care homes in Australia
- Obtaining Permanent Visa.
- Obtaining Visit Visa
- Obtaining Special Permission to marry a Visit Visa holder by a Citizen of Australia.
- Appeal by a Visit Visa holder for Permanent stay in Australia.

The actual procedure followed for these purposes may not be the same as stated in this story. Therefore, anyone interested in these matters should check with the High Commission for Australia in Sri Lanka.

Experience The Alzheimer's Disease From A Caregiver's Diary

January 1, 2009

It was our 40th Wedding Anniversary, our children, Niraj and Monika arrived in Sri Lanka from abroad with their families to organise and celebrate the occasion. They selected a Hotel in the outskirts of Colombo and invited some of our friends and relatives to join us at lunch and spent the rest of the day with us.

After the lunch was over, our children and the guests were engaged in various acts such as swimming in the pool, playing games and discussing current politics. My husband and I went round, thanking each and everyone and got back to our seat, which was specially constructed and decorated for the occasion.

My husband turned to me and said:

“I have lost track of my wife, I feel sleepy. Could you please help me to go to my bed room?”

I thought he was playing the fool with me and said:

“Dear, I told you not to take anything more than a glass of Beer; you seem to have taken too many. Now please don't create a scene here on this special day.” Suddenly he asked,

“Why, what is special about today?”

I got stunned and sent word to my brother-in-law, the youngest brother of my husband, a practicing Doctor who was also an invitee and was having a game of cards with his friends. When he arrived, I started to say about what happened, but he made a signal to me to be silent. He examined his brother, turned to my son and said:

“I think he will need some rest. Please arrange a room in the Hotel.”

My son said, the Hotel has already reserved a room for them and it could be used at anytime. They took my husband to the room and made him sleep. A little later my brother-in-law came out and said:

“Don't worry, I think he has got a mini stroke which resulted in the memory lapse. This is symptoms of what we call Dementia. With little rest, he will get over it for the time being, but we will have to be watchful of his behaviour in the future.”

In terms of the booking, we have to leave the Hotel at 6 p.m. Almost everyone, except the close family members, have left the Hotel.

My Son and I went into the room where my husband was sleeping and woke him up. He looked at me and asked,

“What time is it ?”

I said:

“It’s six o’clock and time to go home.”

He said “No problem, give me two minutes.” got up from the bed, adjusted his trouser and shirt and said:

“Okay, I am ready” as if nothing has happened to him. We were very happy, walked to the place where our vehicle was parked, got in and went home in two hours time.

April 4, 2009

I was writing letters to my children stating that their father is in good health, doing his routine work, helping me with marketing and so on, when my husband came and told me that he wanted to get his haircut. I said O.kay and gave him some money and told him to go to the usual place. He used to get his hair cut in a particular place, because, he found it was very clean and the staff were friendly. Usually, it takes about an hour, but that day even after one and half hours, there was no sign of his return. I thought, being a weekend, they may have had more customers and my husband was waiting for his turn.

When he didn’t turn up even after two hours, I got alarmed and went to the saloon and made inquiries from the girl at the counter. I got a shock when she said, he never came there. I telephoned his brother and told him about the situation.

He almost shouted at me and asked why I allowed him to go alone. I told him, he was normal and did things on his own during the last three months. He told me to return home and promised to pick me up to go in search of my husband. As soon as I finished the call, my mobile phone rang and I thought it was my brother-in-law but it was a lady’s voice. Sumitra, my neighbour telephoning from a super market. She asked me, where I was and when I said I am closer to home, she told me that my husband was waiting for me near the Cashier’ counter with the goods purchased but without money to pay for them. I told her to stand by him, informed my brother- in-law about the changed situation and went to the super market.

As soon as I arrived, he said:

“I am beginning to forget things, here is your list, check whether I have bought everything you wanted.”

and gave me a list, which I gave him the previous week to purchase at the same super market. He did infact, purchase them and it appeared that he had kept the list in his shirt pocket and found it that morning and thought it was a new list given by me to purchase on that day. There was no talk about the haircut or the saloon. I said:

“Good, you have bought everything I wanted, thank you very much; come, let us go home.”

I thanked Sumitra, settled the bill with the cashier and took my husband home.

My brother-in-law was already there. He told me not to let him go anywhere, alone. I agreed and our life continued without any problem.

August 17, 2009

We were invited by Kiran and Varuni, our friends living down the same lane, for the marriage of their son at the family church. We went early and were seated in the second row. We had a clear vision of what was going on and I saw Kiran standing next to his son, signaling his wife to go near his daughter-in-law. My husband turned to me and said:

“I didn’t realise David had a daughter big enough to be given in marriage.”

I asked him, which David he was talking about and he pointed at Kiran who was standing in front of us. I realised, he was getting confused so I said:

“Yes, children grow very fast now.”

He remained silent for some time. I wanted to correct him that it was Kiran’s son and not David’s daughter. I said:

“Kiran’s son who is getting married today is two years younger to our son”.

He responded:

“Yes, I remember, they used to play together.”

After the wedding service, we were taken to a hotel for dinner. While at dinner, I told my husband that the food was very tasty and he agreed with me. When it was time to leave, we saw Kiran and Varuni coming towards the guests to thank but my husband leaped forward and said:

“David, the wedding arrangement was great, the food was very tasty, thank you very much, and we are off, Good Night”.

Thank God, the place was noisy and Kiran didn’t hear a word of what my husband said. Kiran, like what he told others, said:

“Thank you and Good Night”.

I do not know from where my husband picked up the name ‘David’ because on our way home he said:

“David is lucky, the weather God has been kind to him.”

I realised, only when he gets tired he is confused, so I decided to confine him to the house as much as possible.

October 20, 2009

It was 6 a.m, our female cook has gone to her village to see her children and I was preparing tea for us in the kitchen.

December 5, 2009

My husband was listening to the morning news on the radio and there was no one else in the house. Suddenly, I heard him complaining about my cooking and not keeping his things in the proper place to someone. I could not see who it was, so from the kitchen I asked him as to whom he was complaining about me. He said:

“Jeevan and Maya.”

Jeevan and Maya are our friends living down the same lane. Daily at 5 a.m. they go together for the morning walk and on their way back, some days, they used to drop in at our place for a small chat. I offer them a cup of tea, which they enjoy. When I came out of the kitchen with four cups of tea, there was no one, except my husband. I asked him:

“Where are Jeevan and Maya ?”

He pointed at the empty sofa and said:

“They were seated there, they must have left; you took such a long time to prepare them a cup of tea ?”

It was only then that I realised, no one could have come in because I have still not opened the main gate. When I told this to my brother-in-law, he said, he may have hallucinated the sight of them.

It was a normal school day, my husband and I were standing near the main gate, watching children in different school uniforms going to their school. My husband turned to me and said:

“I feel very sorry for these children. They have to go to school even on a Sunday.”

I realised that he was confusing the day and said:

“Unlike our times, these children have a lot to learn, so they need to go to school even on Sundays.”

He then asked,

“Has Monika gone to school.”

Monika is 28 years of age, married two years ago and now living in U.K. Infact, she was here with her husband in January for our 40th Wedding Anniversary. I said:

“She is getting ready.”

His response was to tell her to hurry up, otherwise they will get a shelling from her class teacher when we go for the Parents Teachers meeting next month. Perhaps, he remembered something, which happened several years ago.

February 3, 2010

The neighbour's forum organised a Seminar on Environment at the Community Centre Hall and we were invited. My husband being one of the oldest residents in the area (his father was born in the house in which we are living now) was called by the organizer to say a few words before the seminar proper commenced.

My husband proudly accepted the invitation and went to the stage; but instead of speaking on environment, he started complaining about the frequent break down of electricity in the area and also about the unannounced water cuts. He blamed the administration for its inefficiency and corruption. When he was about to start on a new topic, I ran to the organizer of the event and told him about my husband's recent changed behaviour and requested him to stop him from speaking any further. He agreed, went near my husband, thanked him for the speech and said, he will call the next speaker. My husband came down from the stage as if he had just finished addressing the United Nations General Assembly. I did not want to take him home immediately. We waited there till they announced the tea break at 10 a.m. When we returned home, he was very tired so I let him sleep for some time. When he got up at 1 p.m. to have lunch, he was quiet normal and unaware of what happened in the morning at the Community Centre Hall.

In the evening, I told my brother-in-law about the day's incident and he told me to get his blood sugar and blood pressure checked the following morning at a nearby 'Medi Lab' and have the reports ready for him to have a look at it.

My husband has been treated for Diabetes and Hypertension for some time and we have been able to keep both under control. The reports we received that day indicated both to be above the desirable level. My brother-in-law told me that one of the reasons for his changed behaviour could be due to that and made some changes in the daily dosage of medicines and told me to repeat the tests after one week and let him know the results.

April 4, 2010

Our son and his wife were due in Sri Lanka to attend a wedding. Whenever, he comes to Sri Lanka, he used to stay with his in-laws and visited us daily. My husband finished his breakfast and with a cup of tea in his hand was seated in front of the Television. I was having my breakfast when the doorbell rang. I told my husband to look through the peephole to see who it was. He did that and told me it was a lady and a gentleman. I did not want him to open the door without making sure who it was, so I kept my breakfast, washed my hands and looked through the peephole. It was our son and daughter-in-law. I opened the door and let them in and told my husband that it was Niraj and Anika who have come to see us. He asked:

“Which Niraj ?” with little or no interest in them.

It was no surprise to them, because I have written and kept them informed of his changed behaviour. They both hugged and kissed him and let him sit in the place where he was seated earlier.

Anika gave me the invitation card for her sister's wedding reception. They had lunch with us and left in the evening.

It was in the night, memories of my Husband's behaviour at the wedding of Kiran's son and at the 'Neighbour's Forum' came to my mind. I was thinking whether I should take another risk in taking my husband to this wedding reception. Since I did not want to decide on my own, I spoke to brother-in-law about it. He too did not want to force a decision on me but only said:

"If I were you, I will not take him."

Although he was younger to me, I have high regard for him and I accepted his advice on the matter. My new problem was, should I go alone and is it proper for me to leave my husband at home and attend a function like this. What will people think of me? Again I asked my brother-in-law about it and he said:

"I don't see anything wrong in your attending the reception alone, people will understand, also it will give you an opportunity to explain your husband's present condition to those whom he knew."

It was an appropriate advice but I could not take it to my heart. I have already started feeling guilty. It has never happened in our life, attending a wedding reception without my husband. I decided, therefore, to send a regret note and it was the beginning of our isolation in life.

June 1, 2010

I was reading the letters received from our children. They were very concerned with their father's behaviour and as a result, the difficulties faced by me. They were united in their request that something be done to improve his condition. When I told my brother-in-law about their suggestion, he told me that he has already thought about it and was infact, waiting for the return of one of his colleague, a Neurologist, presently on overseas leave.

My husband being confined to the house, I was not able to go out even to attend to personal matters like paying utility bills and withdraw cash from the Bank to meet our day-to-day expenses. I have to depend on others and that created additional problem for me.

June 16, 2010

My brother-in-law telephoned and told me that he has an appointment to see the Neurologist at 4 p.m. at his residence. He told me to be ready and that he will come and pick us. When I told my husband about the appointment with Doctor, he asked me whether anyone in our family was sick. I told him it was for a general check up and it is being done at the request of his brother. He did not protest.

On arrival at the Doctor residence, we were met by him at the entrance.

We were seated in his sitting room like normal visitors and discussed everything, except my husband's illness. Finally, the Doctor turned to my husband and said:

"I have just returned from U.K after attending a conference on diseases that affect people over 60 years. How old are you and how is your health?"

My husband said, his health was Okay but he must check with his wife about his age. The Doctor, pointing at me asked my husband about me. He said:

"She is my wife and the other person is my brother. He is a Doctor."

I think the Doctor got mixed signals. He smiled and said:

"Now I will tell you about me. Please listen carefully and repeat them....., I am Dr. Sujith working at the General Hospital, Colombo, I live in Nugegoda. I travel by car to the Hospital."

My husband repeated as "I am Dr. Sujith.... Working in Nugegoda Hospital" and stopped. The Doctor said :

"Please continue."

My husband also said: "Please continue" The Doctor again said:

"Please repeat from the start."

My husband also said: "Please repeat from the start."

I think the Doctor got what he wanted; but he did not want to discuss anything in the presence of my husband. He told my brother-in-law that he will call him in the night and gave him two request notes written on his personal letterheads.

He told my husband to look after his health and told me to look after my husband. All of us thanked him and left the place.

June 17, 2010

My brother-in-law telephoned and told me that the Doctor had wanted him to get some tests done on my husband and wanted us to be ready to go to a close by Private Hospital to get it done at 8.30 a.m.

He took a day's leave and we spend the whole day in the hospital and completed all the tests. We collected some reports the same day and others were due, two days later.

These habits must change and change as soon as possible, because our life in this world is very short and we don't live forever even in the other place already reserved for us.

June 20, 2010

My brother-in-law got an appointment to see the Doctor with the reports at 4 p.m. at his residence. The Doctor wanted only me and my brother-in-law to see him. I made arrangement with one of his friends to be with my husband during my absence.

After persuing the reports, the Doctor was of the opinion that my husband is in the early stage of Alzheimer's disease. However, in order to confirm his diagnosis, he wanted some of those test repeated after three months and until such time he did not favour any treatment except the usual dosage of Vitamins. He also wanted his Blood Sugar and Blood Pressure kept under control.

September 17, 2010

My brother-in-law reminded me of the tests that have to be done after three months. He came home, picked us and went to the same Private hospital. By noon all, the tests were done and some Reports were given to us. We were requested to collect the other reports in two days time.

September 20, 2010

We got the appointment to see the Doctor with the reports at 4 p.m. at his residence. Like the last time, I arranged with his friend to stay with my husband. Having studied the new reports, he formally confirmed his earlier diagnosis of my Husband's Alzheimer's disease.

Thereafter, a discussion took place between the Doctor and my brother-in-law, mostly centred on medical terms about which I understood very little.

Finally, he turned to me and said:

“There is, at present, no cure for Alzheimer's disease. Medication available can only slow its progression. I will give a prescription, follow it and report the progress to me after one month. In a situation like this, the most important thing is care giving to your husband. Please draw up a plan with your family members and work accordingly.”

We thanked the Doctor, came out and went straight home. As I got off the car, I thanked my brother-in-law without his help I could not have done even half of what we did. He said:

“Please remember, he is my brother.”

November 15, 2010

I was going through the day's mail and found among others a 'Get Well' card addressed to my husband. It was from one of his long time friends presently living in U.K. He may have got to know about my husband's condition through our daughter living close to his home in U.K. The message in the card read:

“Even if you forget to take your medicines as prescribed by your Doctor,
Do not forget your daily dose of Laughter.”

Unfortunately, my husband was not in a position to read and laugh over that message. He also enclosed a newspaper cutting on Alzheimer’s disease, which was very useful to me. I thought I must record some extracts in my diary.

- Alzheimer’s disease is an incurable Neurological disorder which destroys brain cells.
- Alzheimer’s disease is different from everyday forgetting. It is a condition that permanently affects the brain and over time, makes it harder to remember even basic things like how to eat or drink water. Eventually, the person may have trouble remembering the names and faces of family members or even who he or she is.
- It is important to know that Alzheimer’s disease does not affect small children. It usually affects people over 65 years of age.
- Researchers have found medicines that seem to slow the disease down. And there is hope that someday there will be a cure.

- You may be aware, that your brain works by sending signals. Chemical messengers, called Neurotransmitters, allow brain cells to communicate with each other. Usually a person with Alzheimer’s disease has low amount of Neurotransmitters. They also develop deposits of protein and fibre that prevent the cells from working properly. When this happens, the cells can’t send the right signals to the other parts of the brain. Over time, brain cells affected by Alzheimer’s disease also begin to shrink and die.
- Researchers also think genes handed down from family members can make a person more likely to get Alzheimer’s disease. But that doesn’t mean everyone related to someone who has Alzheimer’s disease will get the disease.

December 21, 2010

Despite medication, my husband’s behavioral changes continued. The changes affected not only his memory, it also affected him physically and socially. In this situation, we had to engage the services of a semi-professional caregiver to my husband. After that life became little easier for me, but with a female cook and a male caregiver, I could not leave them alone at home and go about doing things the way I would like to but when necessary, I made arrangement for someone to be at home when I went out on personal work.

January 1, 2011

It was our 42nd Wedding Anniversary, two years since we had that great celebration in the Hotel. I was seated alone, giving me company was the female cook and the male caregiver. They were doing it as of necessity and not for the love of me or out of compassion. There were no visitors and no telephone calls. My husband's Alzheimer's has erased past memories of all the people known to us. I cannot think of any other reason why many of our numerous friends and relations were suddenly scarce.

Unfortunately, our society has become habituated to visit only people who visit them and speak on the telephone only to those who speak with them. These people don't give even a rare thought of the difficulties of those not visiting them or not telephoning them.

**“Releasing a book is like having a baby;
Fun to conceive but hell to deliver”**

I thank all those who helped me with the release of
this book

May, 2011

A Short Story Based On A Family
With A Sufferer Of
ALZHEIMER'S Disease.