

# Developing standards to ensure care and quality of life of people with dementia in care homes



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A1 Snehanjali  
Silver Innings Helpline  
at**

**IFA 12<sup>th</sup> Global Conference on Ageing**

**10<sup>th</sup> to 13<sup>th</sup> June 2014  
Hyderabad**





# 15th June



## World Elder Abuse Awareness Day

## Elder Abuse is a Crime.

## Report It & Stop It

**मेरा संसार ! आपका संसार !! हमारा संसार !!**

**बुजुर्गों पर उत्पीड़न से मुक्त संसार .....**

**My world ! Your world !! Our world !!! Free of Elder Abuse ....**

# Old Age in India

- ▶ In India, old age was never a problem.
- ▶ Earlier, the elder persons in the family were respected
- ▶ Times have changed. The elders are treated as burden , often neglected / ignored and the story is different if you suffer from some form of Dementia or you are Caregiver



# Dementia Effect

- ▶ Dementia is an progressive illness that over time affects the capacity of individuals to make some or all decisions about their everyday lives, including their money, health and welfare.
- ▶ It gradually affects their **ability to communicate, reason and act** in their own interests. **This severely compromises their ability to stand up for their own rights and leaves them vulnerable to abuse.**



# Dementia and Discrimination

- ▶ People with Dementia face widespread discrimination for a number of reasons:
- ▶ Because Dementia happens to people who are 60+.....this country not for 'old'..... age discrimination
- ▶ Stigma attached to dementia
- ▶ May not have the capacity to challenge abuses of their human rights or to report what has occurred.
- ▶ People with dementia and their carers face a poorer quality of life than the general population.



# Caregivers 'Care'

- ▶ The immediate family members of 'patients' are often 'elderly' themselves and have their own medical problems.
- ▶ In Alzheimer's disease although the 'patient' has the disease, the family members suffer the most
- ▶ **Physical, emotional and economic pressures** can cause great stress to families and caregivers, and support is required from the health, social, financial and legal systems.



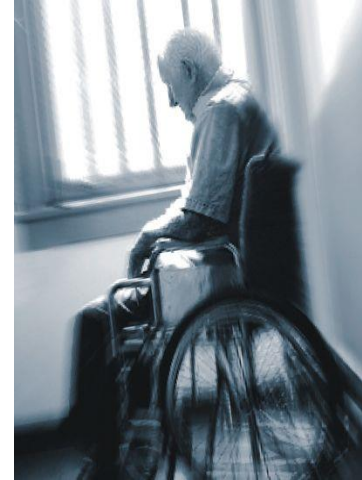
# People with dementia and their Carer experience

- ▶ **Abuse** : Physical , Emotional , Financial
- ▶ Abusive words : OLD ; ELDER'LY' ; DEMENTED ; **PATIENT** ; MAD ; MENTAL ; **INMATES**
- ▶ **Over-prescription** of antipsychotic drugs
- ▶ Stigma
- ▶ **Discrimination** : Gender and Age
- ▶ Indignity
- ▶ Neglect
- ▶ Harm
- ▶ Stress



# Case Study1

- ▶ Son working in MNC could not handle his restless AD father , admitted his Dad in Nursing/Care Home .
- ▶ Could not visit frequently ,visited after 15 days & was **Surprised to find father Passive & dull** . Took him home & found **Bruise mark on hand & legs** – liked Tied down , **found him drugged , got huge bill with 15 unnecessary medicines , no Activity**





## Case Study 2



- ▶ Daughter in law could not manage the Stress of handling Cheerful & overactive Dementia Pa in Law, admitted him in Well known Dementia Care facility away from city with lots of hope
- ▶ Visited after couple of months , **found him Weak & Tired with bundle of Unwashed Clothes , Soiled Bed sheets & unchanged Diapers , Smelly Room**

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**HOW TO  
COMPLAIN**

## Case Study 3



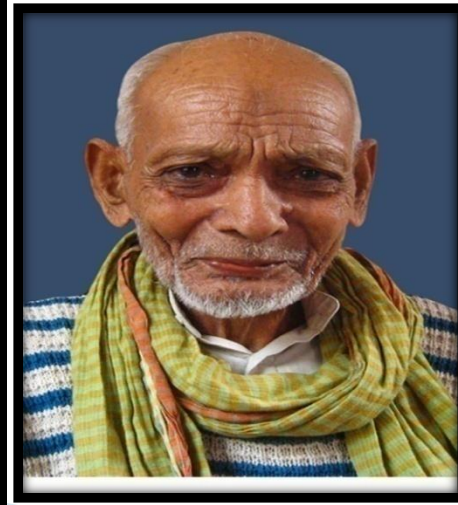
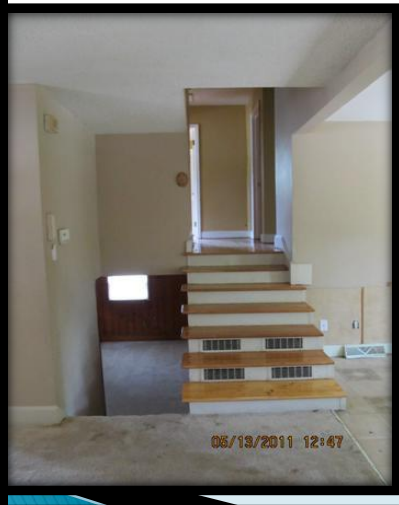
### Consumer Action

- ▶ A NRI son admits his AD mother to Elder Home
- ▶ After few months Visited mother, founds **Staff untrained, inefficient medical support , No Spiritual facility, No Counselor, No Psychologist , Average Food quality– his complaint was ignored**
- ▶ Unfortunately Mother passed away after 2 years and Son **still running Pillar to post to Get the Refund Deposit and Justice for Excess Billing**

*Grievance Redressal Cell*



Slippery Tiles , Unfriendly Staff , Scared Elderly , Lonely Elderly  
Non Elderly Friendly Infrastructure, Untrained & Inadequate Staff  
Management : Top to Bottom Approach



# Rights

- ▶ People with dementia are frequently denied the **basic rights** and freedoms available to others. At some places, **physical and chemical restraints** are used extensively in care facilities
- ▶ An appropriate and supportive legislative environment based on internationally accepted human rights standards is required to ensure the highest quality of service provision to people with dementia and their caregivers.



# Rights should eMPOWER



- ▶ People with dementia and their carers (family members and friends) have the same human rights as every other citizen.
- ▶ **The Rights should aim to empower people with dementia, those who support them and the community as a whole, to ensure their rights are recognized and respected.**

# Charter of Rights for People with Dementia and their Carers in Scotland

- ▶ **Human rights-based approach** (known as the “**PANEL**” approach, endorsed by the United Nations).
- ▶ It emphasises the rights of everyone to:
- ▶ **Participate** in decisions which affect their human rights.
- ▶ **Accountability** of those responsible for the respect, protection and fulfilment of human rights.
- ▶ **Non-discrimination** and equality.
- ▶ **Empowerment** to know their rights and how to claim them.
- ▶ **Legality** in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements



# Participation

- ▶ Enable them to exercise their right to participate in decisions which affect them.
- ▶ **Access/participate to recreational, leisure and cultural life in their community.**
- ▶ **Right to full participation in care needs** Mapping ,assessment, planning, deciding and arranging care, support and treatment, including Advanced decision making (not in India )



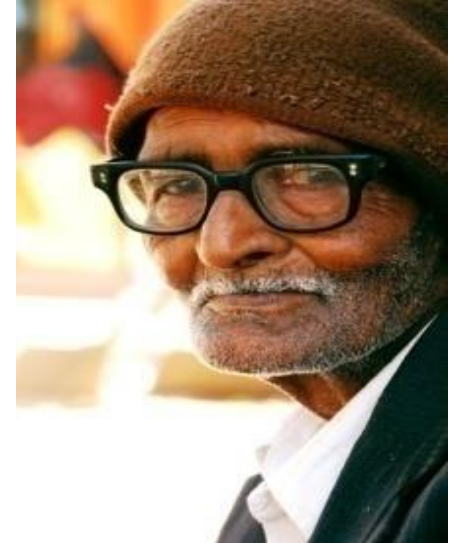
# Accountability

- ▶ Right to be able to **enjoy human rights and fundamental freedoms in every part of their daily lives** and wherever they are, including full respect for their dignity, beliefs, individual circumstances and privacy.
- ▶ **Public and private bodies, voluntary organisations and individuals responsible for the care and treatment of persons with dementia should be held accountable** for the respect, protection and fulfillment of their human rights and adequate steps should be adopted to ensure this is the case.



# Non-discrimination and equality

- ▶ **Right to be free from discrimination** based on any grounds such as age, disability, gender, race, sexual orientation, religious beliefs, social or other status.



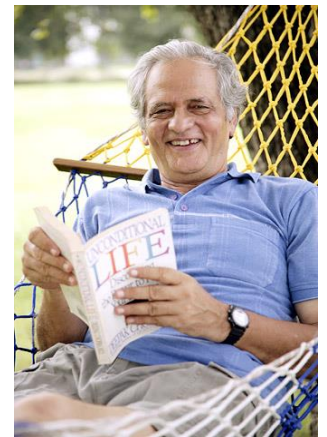
# Empowerment

- ▶ Right to have access to appropriate levels of care providing **protection, rehabilitation and encouragement.**
- ▶ Right to help to **attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.**
- ▶ Right to access to **opportunities for community education and lifelong learning.**
- ▶ **Right to access to social , financial and legal services to enhance their autonomy, protection and care.**
- ▶ **Right to health and social care services.**



# Legality

- ▶ Right to have the **full range of human rights** respected, protected and fulfilled.
- ▶ Right to live in **dignity and security** and be free of exploitation, violence and physical, mental or sexual abuse; economic, social and cultural rights including the right to an adequate standard of living including, social protection;
- ▶ Right to the **highest attainable standard of physical and mental health.**
- ▶ **Right to information**, to participation in decision making and, where rights are not observed, the **right to seek remedy through effective complaint and appeal procedures.**
- ▶ Right, regardless of diagnosis, to the same civil and legal rights as everyone else.





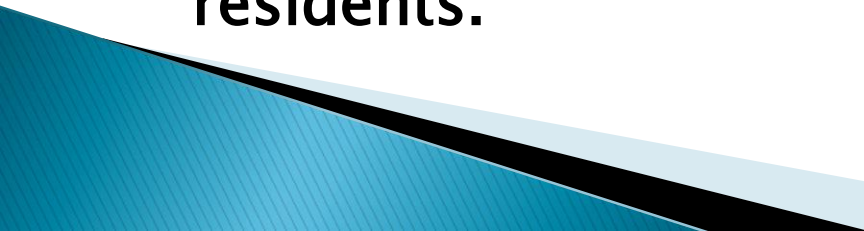
A Silver Innings<sup>TM</sup>

Assisted Living Elder Care Home

# Rights of Residents at A1 Snehanjali

- ▶ **Right to voluntary participation** : Each resident's participation shall be voluntary and they shall be provided information to make an informed choice of participating and accepting services.
- ▶ **Right to practice own religion** : Every resident is free to practice his/her own religion, without disturbing other residents
- ▶ **Right to medical care** : Every resident has the right to have private communications and consultations with physicians of their choice and of A1 Snehanjali / Silver Innings, as per terms and condition of A1 Snehanjali
- ▶ **Right to present grievances by residents and family** : Every resident, plus family will have the right to express grievances if any to the centre manager for redress

# Rights of Residents at A1 Snehanjali

- ▶ **Right to confidentiality in treatment** : Every resident has the right to confidentiality, privacy and treatment.
  - ▶ **Right to receive needs based services** : If required, every resident has the right to need based assessment when required. Additional costs would be provided by the family / guardian / self.
  - ▶ **Right to dignity** : Every resident has the right to live respectfully and enjoy a dignified life.
  - ▶ **Right to have family visit** : Every resident shall have the right to receive visits from family members and other adults as per the terms and conditions of A1 Snehanjali.
  - ▶ **Responsibility to respect personal rights and privacy** : Every resident shall follow all the rules of the home and will respect the rights and property of other residents.
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# Challenges

- ▶ Despite the magnitude, there is gross ignorance, neglect and services/facilities are scarce for people with dementia and their families.
- ▶ It is to be noted that the demand for services and facilities for Aging population will increase quite significantly. The task of meeting this need will be more challenging and urgent.
- ▶ As the domain of Care Homes for Dementia is emerging as a sunrise industry, there is no set guidelines nor monitoring agency. Hence it's social and legal responsibility of government and civil society to develop best standard of care & Rights for people with dementia which can not only provide care and services but also quality life .



Silver Inning Foundation







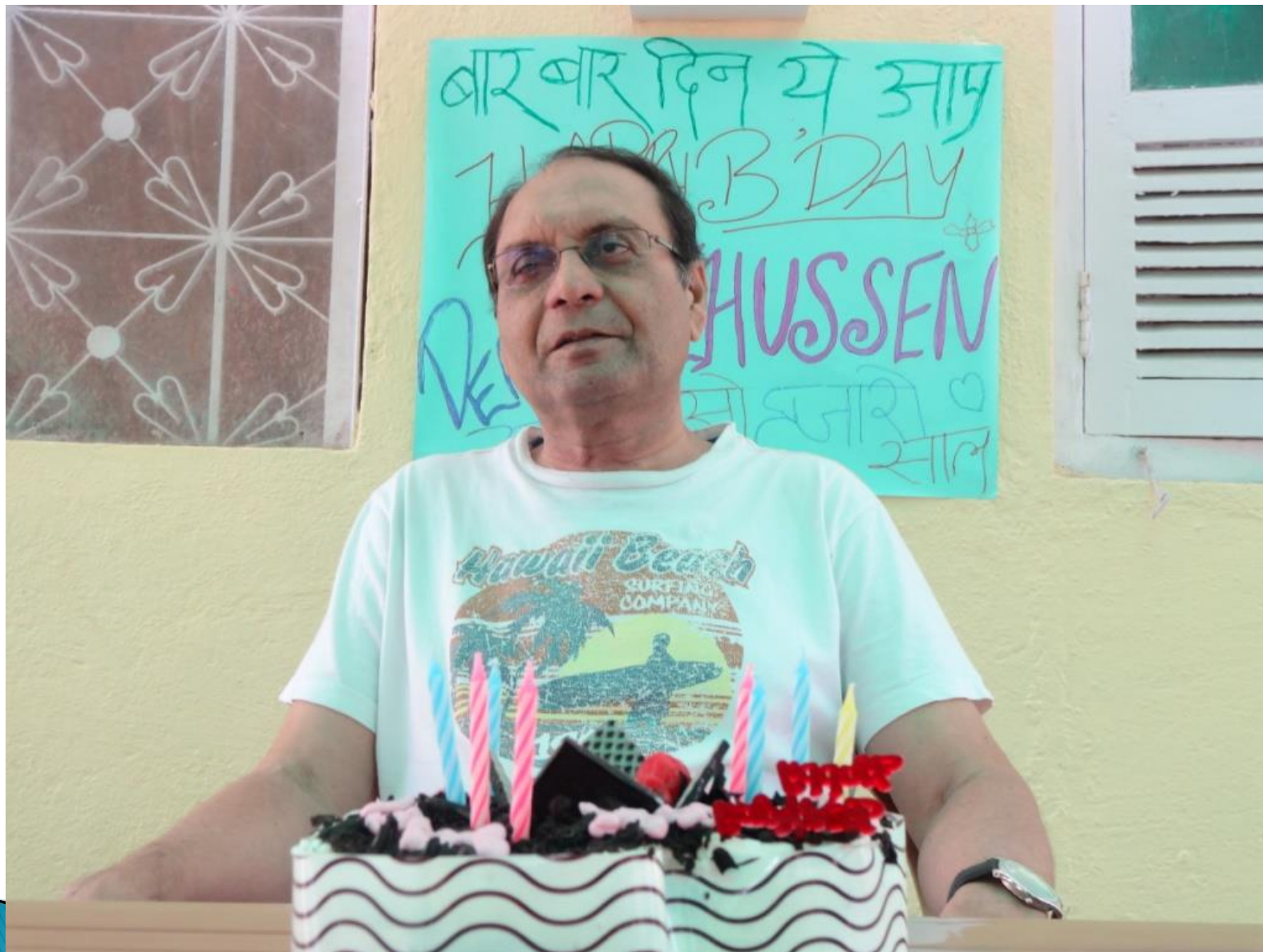


















A Silver Innings™  
Assisted Living Elder Care Home







वै के प्रायना  
रोकथाम

सुख्य लमठा  
मारी  
कुचनने  
जेसा  
सीने मे बाए और  
पनीना

संबधित लमठा  
पनीना  
सास लेने मे  
परिशानी

कमजोरी  
शकान

पेट  
लकल

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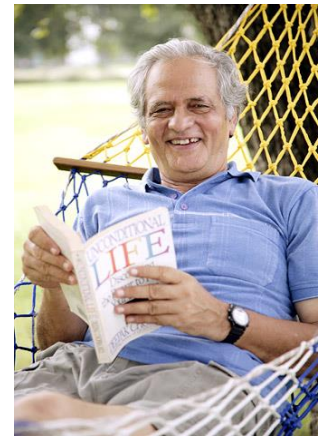
# Summary

- ▶ People with dementia and those who care for them should be treated with dignity and respect, and should have access to high quality care, that is based on personal needs and preferences, rather than prejudiced assumptions about dementia. For people with dementia to be able to play a full part in community, society must prioritise the eradication of discrimination and tackle the stigma attached to dementia.
- ▶ There is need to build Ethical and Legal guidelines and standards for home and care facilities to Enrich the Lives of people with Dementia and their carers .
- ▶ We need to work on **Care** rather than on **Cure**



- ▶ **Putting old parents in old age homes / care homes should be considered as a secondary / last option and not as the only option for taking better care of the elders.**
- ▶ **Parents / Elders are a treasure that children/we should guard zealously. Treat your parents/elders as assets not liability. Let them feel wanted and not a burden..**

# We are Human Being too....



# References

- ▶ Reference: Charter of Rights for People with Dementia and their Carers in Scotland : <http://social.un.org/ageing-working-group/documents/Alzheimer%20Scotland%202.pdf>
- ▶ WHO : Dementia Fact Sheet : <http://www.who.int/mediacentre/factsheets/fs362/en/>
- ▶ A1 Snehanjali, Silver Innings Assisted Living Elder Care Home
- ▶ SPAIN : “The Act for the Promotion of Personal Autonomy and Care for Dependent Persons” configures a new citizenship right. A right for the elderly or disabled people that need help in carrying out the basic activities of daily living
- ▶ RIGHTS OF RESIDENTS IN ASSISTED LIVING RESIDENCES , NYC , Susan Somers

# My world, Your World, Our World Free of Elder Abuse

## Remember Those who Cannot Remember

Its Silver Inning Foundation Presentation



# Thanks



IFA 12<sup>th</sup> Global Conference on Ageing

**'Health, Security and Community'**



**INPEA WEAAD 2014 Global Event**

**United Nations International**



**World Elder Abuse Awareness Day (WEAAD) 15<sup>TH</sup> June**  
**10-13 June 2014 - Hyderabad, India**