Rehabilitation and Residential Care Needs of the Elderly
(Clinical Practice Guidelines)

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I) Introduction

Many senior citizens of our society are able to live a very meaningful and independent life, but at the same time the fact remains that there are some who are unable to do so. Elderly individuals, who develop dementia, develop progressive and more often than not irreversible decline in their cognitive abilities, neurological deficits and behavioral and psychological symptoms associated with dementia. This results in considerable impairment in their ability to carry out activities of daily living and to lead an independent and meaningful life. A rehabilitation program may help them to overcome this disability and to live life meaningfully and as independently as possible. Some of the senior citizens, who are unable to lead an independent life in their own homes, may require residential care facility. These clinical practice guidelines suggest some of the rehabilitative measures to improve the quality of life of senior citizens. Though, literally speaking 'rehabilitation' means 'to restore to a former position or status', in case of senior citizens it means to make efforts towards improving their quality of life.

II) Review of literature

A) The changing demographic profile of the population of India

Demographic ageing is a global phenomenon. India's booming population of above one billion people; the second most populous country in the world and improved life expectancy have led to an increasingly large number of people over the age of 60. There are now 77 million elderly people in India and this number is expected to rise to 100 million in 2013 and to 198 million in 2030. The special features of the elderly population in India are as follows.

1) A majority (80%) of them are in the rural areas, thus making service delivery a challenge. The government pension scheme currently reaches only 2.76 million out of 28 million elderly people, mainly urban.

2) Feminization of the elderly population (51% of the elderly population would be women by the year 2016.

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3) Increase in the number of the older-old (persons above 80 years).

4) A large percentage (30%) of the elderly is below poverty line (Gravis, 2004).

These demographic changes has been accompanied with a fast changing family structure due to forces like urbanization and migration which are not quite conducive to the welfare of the elderly (NISD,2005). The trend clearly reveals that ageing will become a major social challenge in the future and vast resources will be required towards support, care and treatment of the older persons. On the other hand, the historical – cultural task of care and respect for the elderly within the family and society in India is still prevalent, although on the decline. A multi-pronged strategy for strengthening the traditional care system and evolving appropriate framework for services is the need of the hour.

In order to cope with these problems, it is necessary to educate & impart training to persons concerned with the welfare of the older persons and to develop trained manpower, which can take care of older persons within the community setting. Thus guidelines in rehabilitation of the elderly will aid professionals, paraprofessionals, NGO's and other private or government bodies to care for the elderly in a more structured way.

Setting up rehabilitation or residential care facilities especially for the elderly is a challenging task. The Indian government (like the ministry of social justice and empowerment) does have welfare schemes for the elderly, but a lot of input is required from NGO's, medical professional and paraprofessionals to meet the requirements.

B) Need for rehabilitation programs for senior citizens

Rehabilitation helps a person who is recovering from illness or injury to regain as much function as possible. The aim is for patients to become as independent as possible despite his/her disabilities. Rehabilitation also aims to teach strategies for ongoing disabilities. However in the elderly, the word rehabilitation has a different connotation. It involves promoting the welfare of the elderly, advocating a general national priority to their problems and needs and for organizing services. The services to implement this includes residential care, day care, geriatric care, medical and psychiatric care, recreation, financial assistance and counseling. These services are however primarily urban based (Sawhney, 2005).

C) Types of rehabilitation services

Various types of health and social services are in practice today.

1) Community based interventions
These are important as early interventions as they improve the subjective well being and quality of life of the elderly. These services also strive to give a greater degree of functional ability and independence. It is however important to search for programs which are cost effective (Shapiro, Taylor, 2002).

a) Outpatient clinics: These clinics are important for assessment and follow up of mobile patients. There are advantages when these clinics are staffed jointly by internists and psychiatrists. In some areas memory clinics have been developed for assessment of patients with early memory problems (Wilcocks, Bucks, 1999).

b) Domiciliary visits: Increasingly assessments and treatments are offered in the patient's home, which is convenient and more relevant. In Europe and US, community psychiatric nurses act as a bridge between primary care and specialist service. Domiciliary visits also reduce the rate of hospital admissions (Readon et al, 1995). It has also been argued that if resources are limited, visits should be directed to patients living with their families than those living alone. This is because the former can remain at home, whereas the latter will need admission before long even with extra input (Gelder et al, 2001).

c) Day care: Day care should provide a full range of diagnostic services and offer both short term and continuing care for patients with functional or organic disorders, together with support for relatives. There are few day care services by NGO’s in India (i.e. Help age India) and also state governments.

Definitive criteria for referral have not been essentially established. Some of the targeting criteria for community based services can include dependency in 2 or more activities of daily living, no family support, dementia, many long-term illnesses, and many hospital stays (Borgenicht et al, 2005).

2) Other forms of rehabilitation

a) Residential care and nursing care: Residential care involves accommodation, ranging from independent housing to sheltered housing schemes. In residential homes, the needs of the elderly can be met by care assistants with relatively little training. Nursing care involves trained nurses, and is for individuals with more medical problems (Gelder et al, 2001). The residents in both set ups face more cognitive impairment, depression and behavioral disturbances. They also face inadequate quality of medical care. Training the assistants and nurses can improve the functional ability of the residents (Proctor et al, 1999). Studies from Madurai (India) have shown that living in residential homes or even alone is not a barrier.
against social integration, but psychiatric groups face more problems as compared to those with only physical problems (Rao, 1987).

b) Hospital care: This can be either acute or a long term care. Inpatient teams should be able to provide multidisciplinary assessment and treatment of patients with severe mental health problems. There is variation in different areas as to who should be a part of the multidisciplinary set up and whether patients with functional illnesses need to be cared for separately or together with organic disorders (Gelder et al, 2001). However prompt discharge should be the aim in acute set up, because of the vulnerability of the elderly to nosocomial infections. On the other hand acute care set ups are a successful way of assessing the needs of some older people who would otherwise have been admitted directly from their homes to nursing homes (Hutchinson et al 1998).

c) Respite care: It is essentially a professional colloquialism and is a multi-agency response to the needs of carers. Respite care involves care given to the elderly, so that caregivers can take time off to relax or take care of other responsibilities. Respite can vary in time from part of a day to several weeks. It encompasses a wide variety of services including traditional home-based care, as well as adult day care, skilled nursing, home health, and short term institutional care (Dept of health and human services, 2005). Research indicates that respite care decreases family stress and improves family functioning, life satisfaction, attitudes toward family members with disabilities, and the physical and emotional health of the elderly. Respite care significantly decreases the need for costly out of home placements, such as hospitalization, and nursing home care. It also reduces elder abuse (APA, 2003).

d) Home based set ups: Informal care often provided by spouses, adult children, and other family members accounts for most of the care the elderly currently receive in developing countries. Even today, the younger generation in India sees it as their responsibility to care for their elderly, and they are under social and cultural pressure to do so. Care provided at home is often considered the preference of the elderly and, and the cost is most often borne by the family. However, despite the increasing demand for home-based care due to population aging, factors like urbanization, migration, break-up of the joint family system, change in the role of women from being full-time carers, decreasing fertility rates means that future cohorts of elderly will have smaller networks of potential family caregivers (Shah, 2006). Due to all these factors and more, Indian families will need more active help from other supporting services (mentioned above).
**D) Components of rehabilitation programs**

A rehabilitation program is a combination of physical, occupational, and speech therapy; psychological counseling; and social work services to help debilitated persons maintain or recover physical capacities. Rehabilitation is typically needed by patients, especially elderly patients, who have become de-conditioned because of prolonged bed rest (e.g. after a myocardial infarction, heart surgery, or a serious illness). It is often indicated in cognitively impaired. Age alone is not a reason to postpone or deny rehabilitation. However, the elderly may recover slowly because they lack endurance, because they have depression or dementia, or because muscle strength, joint mobility, coordination, or agility is diminished. Programs designed specifically for the elderly are preferable, because the elderly often have different goals, require less intensive rehabilitation, and need different types of care than do younger patients. In age-segregated programs, elderly patients are less likely to compare their progress with that of younger patients and become discouraged (Beers et al, 2000).

1) **The rehabilitation team:**

The rehabilitation team (a specialized type of geriatric interdisciplinary team) coordinates the services needed by these patients and develops and implements a comprehensive treatment plan. Team members may include physicians, nurses, physical therapists, occupational therapists, speech therapists, psychologists, social workers, other health care practitioners, the patient, and family members.

2) **Goals of therapy:**

Establishing goals of rehabilitation helps determine the setting and method of rehabilitation. For the elderly, the goal of rehabilitation is often limited to restoration of the ability to perform as many activities of daily living (ADLs) as possible.

The aim is to establish short-term goals, which are specific and long-term goals, which are more general. A patient's progress in achieving short-term goals must be followed closely for rehabilitation to be efficient. The treatment plan can be used to track progress. The patient is encouraged to achieve each short-term goal and is informed of any changes in goals. Improvements in patient performance are noted in the treatment plan (Beers et al, 2000). Family members can also be trained to give rehabilitative therapy. If feasible, a visiting physical therapist or occupational therapist can be used.
E) Measures to assess needs:

The needs to be assessed include physical, emotional and cognitive. One of the popular modes of doing it is by measuring ‘activities of daily living’ or ADL. The term “activities of daily living” refers to a set of common, everyday tasks, performance of which is required for personal self-care and independent living. It includes eating, bathing, dressing and toileting (Rivlin et al 1988). Ways of measuring ADL are by using scales like Katz scale, Barthel scale or the PULSES scale (i.e. Physical condition, Upper limbs (self-care), Lower limbs (ambulation), Sensory abilities, Excretory, Mental and Emotional Status) (Fillenbaum, 1987). A further modified scale is the “instrumental activities of daily living” or IADL. It captures a range of activities, including handling personal finances, meal preparation, shopping, traveling, doing housework, using the telephone, and taking medications.

Activities of daily living are significant predictors of admission to a nursing home; use of hospital services; living arrangements, use of physician services and research. However cognitive impairment and ADL status are correlated but are separate dimensions of functioning. Not all persons with substantial cognitive impairment have ADL dysfunctions. One recent study found nearly 40 percent of the elderly with moderate to severe cognitive impairment, needing no active human assistance with any of five ADLs (Kennell et al 1989). As a result, studies estimating the extent of need for long-term care services that rely solely on ADL measures will miss a substantial proportion of the target population.

To measure cognitive assessment some of the common scales used are Short Portable Mental Status Questionnaire (SPMSQ), MMSE (mini mental status examination) which also help in determining the type and content of rehabilitation.

F) Various types of interventions:

Interventions from various professionals are required to make a rehabilitation program succeed and improve the quality of life of the elderly. It can take various forms like improving or improvising their physical needs, psychological wellbeing, targeting cognition or enhancing activities of daily living.

1) Activities of daily living:

As mentioned above, activities of daily living include eating, bathing, dressing and toileting. Retraining in these activities requires help from an occupational and physical therapist. Sometimes assistance devices also prove useful. Such devices can be as simple as a long-handled bath
brush or as complex as a wheelchair. For drinking; special cups, Styrofoam glasses or straws can be used. Spoons with special handles and strengthening exercises for gripping can be implemented so as to eat without spilling. Home improvisations for bathing and toileting can be grab bars attached to the wall, bath seat, showers and western style high toilet seats or movable toilet pots.

For dressing loose-fitting tops with front-closing zippers, ties or buttons are most convenient. Physiotherapists also give tips like putting the weak arm or leg in first when dressing and taking the strong arm or leg out first when undressing. Other useful strategies can be removing rugs to prevent tripping, installing railing, painting the last stairs to make them more visible and pasting emergency numbers on the wall (Doolittle, 1999).

2) Neuropsychological rehabilitation:

Neuropsychological rehabilitation can provide both a general framework for intervention and a means of tackling specific issues. As a general framework, it allows for a biopsychosocial formulation within which an understanding and acknowledgement of the person’s cognitive impairments is central. This means, for example, that explanations and advice can be provided to the person and his or her carers, helping them to make sense of some of their difficult and distressing experiences. Specific difficulties can be addressed using methods devised for people with dementia or adapted from those reported to be useful for people with brain injury (Claire, 2001).

a) Reality orientation:

One of the earliest approaches was the adaptation of reality orientation (RO) for use with people who have dementia. It is based on the belief that continually and repeatedly telling or showing certain reminders to people with mild to moderate memory loss will result in an increase in interaction with others and improve orientation. This in turn can improve self-esteem and reduce problem behaviors. In reality orientation, people with Alzheimer’s disease are surrounded by familiar objects that can be used to stimulate their memory. Other materials, such as a family scrapbooks, flash cards, Scrabble games, large-piece jigsaw puzzles, and large clocks and calendars are also helpful. The concept of reality orientation attained widespread acceptance in long-term care settings, but its implementation was not always of a high standard, with interventions sometimes applied in a rather insensitive manner. More recent work has demonstrated that interventions based on the principles of reality orientation can have positive effects on cognition and behavior in the elderly (Larkin, 1994)
b) Cognitive retraining:

Cognitive retraining is a therapeutic strategy that seeks to improve or restore a person's skills in the areas of paying attention, remembering, organizing, reasoning and understanding, problem-solving, decision making, and higher level cognitive abilities. Cognitive retraining is one aspect of neuropsychological rehabilitation.

Types of cognitive retraining (Encyclopedia of mental disorders, 2006)

i) Memory retraining: Memory retraining involves teaching the patient several strategies that can be used to recall certain types of information. For example, rhymes may be used as a memory aid. A series of numbers, such as a phone number with an area code, may be broken down into smaller groups. A person may be taught to go through each letter of the alphabet until he or she remembers someone's name. Use of mnemonics has also proved beneficial.

ii) Organizational skills retraining: This approach is used when the person has difficulty keeping track of or finding items, doing tasks in a set order, and/or doing something in a timely manner. Strategies may include having one identified place for an item (“a place for everything and everything in its place”). In addition, the person can be taught to keep the items that are used most frequently closer to him or her (the front or the lower shelves of a cabinet, drawer, closet, or desk, for example). Items that are often used together (such as comb and brush, toothbrush and toothpaste) are placed beside each other or using a daily or weekly pill box to keep track of medication.

iii) Problem solving: Problem-solving retraining aims to help people define a problem; come up with possible solutions to it; discuss the solution(s) with others and listen to their advice; review the various possible solutions from many perspectives; and evaluate whether the problem was solved after going through these steps.

iv) Decision making: Decision-making retraining is used when a person must choose among a number of options. The goal of this retraining is to help him or her consider the decision thoroughly before taking any action. The considerations may range from such practical matters as money, people, rules and policies, to personality issues.

v) Executive skills: Executive skills retraining refers to teaching individuals how to monitor themselves, control their thinking and actions, think in advance, set goals, manage time, act in socially acceptable ways, and transfer skills to new situations. These are higher-level cognitive skills. Charts and videotapes may be used to monitor behavior, and a variety of
questions, tasks, and games may be used in retraining these skills.

All the above methods have reported gains in targeted areas but not in the generalized sphere according to a randomized control trial done recently (Cahn – Weiner, 2003).

c) **Compensatory memory aids:**

These include day listed diaries, lists, calendars, use of digital watches with beeps etc. Computer and video equipment to monitor and control the environment of the person with cognitive impairment is now being used to support independent functioning.

3) **Physical exercises**

Exercise has been found to have a number of benefits for elderly. It can assist in avoiding, delaying or reducing some of the mobility problems associated with increasing age. It can also help to slow decline in behavior, communication and social participation.

Evidence suggests that only a small number of people aged over 65 —fewer than 20 percent — engage in an adequate level of physical activity, while people who have cognitive impairment are even less likely to engage in such activity (Kramer, 2006).

Walking, jogging, swimming, yoga have known benefits for all ages. However more research is needed to prove what type of exercise is most effective for cognitive thinking, how long do the effects last and how much exercise is needed for continuing benefits.

G) **Caregiver’s perspective:**

Informal or lay care giving is the act of providing assistance to an individual with whom the caregiver has a personal relationship. Healthcare today has resulted in a dramatic increase in the burden placed on a patient’s family and other loved ones. Despite this fact, caregiver burden and burnout are probably greatly under identified by primary care physicians (Kasuya et al 2000).

Studies show that a large majority of caregivers have experienced fatigue, frustration, and stress as a result of care giving. Two thirds of the carers believe that care giving has put a strain on their marriage, and one fourth have felt despair as a result of the care giving experience (Dean, 1995).

Family members and other providers often accept responsibility for the care of those with chronic health needs. Typically, they do this for emotional and economic reasons, not because they are proficient at, or feel comfortable with, the type of care required. As time and illness progress, the responsibility may be met with decreasing enthusiasm, and caregivers may find themselves angry or resentful about this toll on their lives; insight into their feelings often serves only to make
them feel guilty or shameful about their reactions (Kasuya et al 2000).

1) Causes of burnout or burden:

Various factors like a higher frequency of disturbing behavior, caring for a community-dwelling patient, low informal support leading to more depressive symptomatology have been attributed (Clyburn et al, 2000).

Sometimes the caregivers’ own characteristics may play a major role in determining how burdensome and stressful they find their role. These characteristics include such things as gender, availability of support systems, and relationship to patient. It also involves the way the caregiver perceives the patient’s symptoms (whether illness related or deliberate) and his or her attitude and behavior toward the patient. Understanding the origins of caregiver burden has broad implications both in terms of the well-being of caregivers and the quality of support that patient’s receive (Donaldson, Burns 1999).

2) Role of training programs:

Carers need information on the nature of the illness, emotional support and availability of services. They also need help on the emotional aspects of caring, coping with loss, and developing interest outside their caring role. Interventions can be either educational or comprehensive in nature. Educational programs are informative, while comprehensive strategies include ventilation, stress management, counseling, problem solving skills and techniques to handle patient’s behavior and cognitive problems (Gormley, 2000). Individual care plans, including training in behavioral management techniques, pharmacotherapy and social support, targeting specific problems, including aggression and urinary incontinence have also been designed (Hinchliffe et al, 1995).

Comprehensive intervention programs have been found to successfully reduce patient behavioral disturbances, and also improve carer’s mental health (Teri, 1997)

H) Conclusion:

Proper and sensitive care for the aged will ‘add life to years’ for the many neglected and forsaken elderly people now in our midst. The programs for the elderly need to be both, developmental and humanitarian. It is the government as well as the non governmental voluntary sector in our country that need to make the society friendlier for the senior citizens (Sawhney, 2005). Organizations like the Indian Council of Medical Research has recommended introducing the concept of geriatric care into hospital services, developing rehabilitation services for the disabled

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elderly, introducing principles of geriatric medicine in the undergraduate medical curriculum and organizing facilities for postgraduate training in gerontology (Shah, 2006). These steps will further lend a helping hand to this population.

Finally commitment and compassion are needed, for without them no amount of facilities and infrastructure will work. Every effort should be made to prevent the elderly from being segregated from the family. Family support for the elderly also needs to be strengthened economically by the state. It is also necessary to assemble a coherent approach that reflects a genuinely biopsychosocial model and espouses the aims and values of person-centered care.

III) Aims of rehabilitation program for senior citizens

The aims of the rehabilitation program are

• to make their life more meaningful
• to help them to be as much self-sufficient as possible
• to improve the overall quality of life

by enhancing and ensuring optimal utilization of their preserved abilities, minimizing the need of their lost abilities and providing necessary assistance for better functioning.

IV) Planning a rehabilitation program

A) Indications for rehabilitation program

1) Individuals having mild cognitive impairment.
2) Individuals having mild, moderate or severe dementia
3) Individuals having neurological deficits
4) Individuals having BPSD (Behavioral and Psychological Symptoms of dementia)

B) There are some important issues which one should keep in mind while planning a rehabilitation program.

1) Plan and implement as early as possible
   A rehabilitation program should be planned and implemented as early as possible. It should not only be considered for individuals having severe disability but also for the individuals having mild cognitive impairment (MCI).
2) Comprehensive and need based
   (Based on the socio-cultural and urban or rural background)
The program should be comprehensive and devised to help the individuals to overcome the practical difficulties in day-to-day life.

(For example, while assessing the recent memory of the patient we try to find out if he remembers what he had for the breakfast in the morning or for the dinner the previous night. From a practical point of view he does not need to remember it. But he may need to remember if someone had left a message with him for some family member. Thus while recommending a use of diary, he should be asked to write down the message and the names of the sender and recipient. We may not achieve much by asking him to note down in his diary what he had for the breakfast, lunch or dinner.)

It is important to keep in mind the socio-cultural background of the individual while designing a rehabilitation program. A farmer hailing from rural area may have different needs and so would require a different type of rehabilitation program as compared to the program designed for a retired bank officer staying in urban area.

3) **Prioritize the goals**

As one may not be able to implement and achieve too many things simultaneously, it may be a good idea to decide one or two priority-goals at the beginning in the rehabilitation program and work on the other goals after achieving the priority-goals.

4) **Be Innovative**

There may not be readily available answers, techniques or programs for a variety of difficulties faced by our senior citizens and so one will have to be innovative. Look around, think, ask, discuss and you may find an innovative solution to a problem.

5) **Review, modify and upgrade from time to time**

The deficits in patients of schizophrenia or physically handicapped individuals are stable and non-progressive, while the deficits in elderly individuals are likely to be progressive. Therefore one may have to modify the rehabilitation program from time to time according to the changing needs of the persons. One may also consider measuring various types of deficits in different domains at baseline and subsequent improvement using appropriate standardized rating scales.

6) **Be vigilant about the masked (compensated) deficits**

Some of the deficits in the elderly individuals may not be evident in the beginning as they may be compensated in the unvarying and secured environment of the home where many of the needs of the elderly individuals are taken care of by the relatives. These deficits may get unmasked
when the individuals face more challenging circumstances.

(For example, deficits in visuo-spatial orientation may not be evident in the cozy environment of the house where the person may be staying for last 40 years. But the same patient may get lost in the long corridors of the hospital where the day-care-center is situated.)

7) Take into account the other associated problems

Many of the senior citizens may have visual and auditory problems. They may also have other medical problems like arthritis, heart disease, diabetes, hypertension, nutritional deficiencies etc. One of the important issues to keep in mind is ‘elderly abuse’. These problems also will have to be taken into accounts while planning a rehabilitation program for them.

8) Maintain and monitor the quality of care

While providing the various facilities in a rehabilitation program one should strive to attain the best possible quality of care for our elderly individuals.

B) One may follow the following steps for planning a comprehensive rehabilitation program for the elderly individuals.

1) Establishing a rapport, a therapeutic alliance and psycho-education

The first step in planning a rehabilitation program is to establish a rapport and a therapeutic alliance with the individual and his family members or caregivers. For planning a good comprehensive rehabilitation program one needs a lot of inputs from them and it is absolutely essential that in order to get maximum benefit from the program, they have well understood the need for the program and method for its proper implementation. This can only be achieved by giving a good psycho-education to family members or care-givers. Right at the beginning it may be important to address the issue of stress and burden faced by the care-givers and how to deal with it and how to avoid burnout.

2) Assessment of impairment in activities of daily living & assessment of available resources

The rehabilitation program has to be tailor made for each individual and so it will have to be planned depending on the nature and extent of impairment in the activities of daily living. For this purpose it will be useful to find out the daily routine of the individual.

a) Daily routine of the individual

Try to find out from the patient and his relatives about the activities of patient's daily routine, when he was relatively better, a couple of months or years ago and was he happy with that routine or not?

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For example, one may want to know that when the patient was relatively better

i) What time in the morning did he wake-up?

ii) Did he go for a morning walk or did some other exercises?

iii) Was he interested in reading newspaper or watching TV?

iv) Was he working part-time or full-time on regular basis?

v) Was he interested in any extracurricular activities?

vi) Did he like to socialize?

vii) Was he an active member of any organization or a group?

viii) Was he able to use mobile phones and remote controls?

ix) How is his sexual life? (Depending on the socio-cultural background)

b) Which of the above mentioned activities of the daily routine is he still able to carry out reasonably well; for which activities does he need assistance and which activities has he given-up?

These questions would give us some idea about the nature and extent of the impairment which the individual has developed.

For example

i) He may have stopped going to work for last 6 months.

ii) He may have stopped socializing

iii) She may have developed difficulty in cooking, dressing etc which she was able to do well a month ago

b) What are the contributory factors to the development of impairment in the activities of daily living?

Broadly speaking the impairment may be attributed to cognitive deficits, neurological deficits or behavioral and psychological symptoms associated with dementia.

For example

i) Due to cognitive deficit he may be unable to find his way back home and so may have stopped going out alone

ii) Due to parkinsonism he may be unable to take his meals without assistance

iii) Due to development of depression or paranoia he may be avoiding social functions.

3) Assessment of available resources

Having assessed the impairment, one would like to develop strategies to overcome it. But in
to do so, one would need to know about the available resources.

a) Patient's family or caregivers

In terms of human resources, family members are the major asset for the patient who is developing dementia. Therefore, it is important to study the family structure and family dynamics. Participation of family members is very essential for the successful implementation of rehabilitation program.

For example one may want to know

i) Who is the key family member for the patient? For a treating doctor, it may not be possible to interact with each and every member of the family and so he may prefer to interact with the one who is likely to be mainly responsible for the patient care. It may be the spouse, a son or a daughter or frequently a daughter-in-law.

ii) Who takes the decisions in important matters of the family? It may be the eldest son or the patient’s sister who is single and staying with the family. Occasionally it may be a person who actually doesn’t stay with the family but due to his status and position in their community (e.g. a family physician, a village head (sarpanch), a religious leader etc.), family members may prefer to consult him before complying with the recommended program. In such cases one may have to take this person in confidence and seek his approval for implementation of the program.

b) Rehabilitation center, day-care center and the Medical and paramedical staff

For the implementation of the rehabilitation program one may need a rehabilitation center or day-care center in the vicinity, where the patient may be referred for exercise and cognitive retraining or one may require a trained nurse, an occupational therapist, a physiotherapist, a speech therapist, a music teacher etc. who can visit the patient to assess his impairment in different areas and chart-out a comprehensive rehabilitation program for him.

c) Financial resources

One would also have to look at the availability of financial recourses. For example – Who will bear the cost of the therapy? Is patient covered by any medical insurance? Are there any trusts, social or community groups which provide financial help to these patients.

C) Charting-out a rehabilitation program

A comprehensive rehabilitation program would include certain I) common general measures which one would like to observe for all the patients and certain II) specific measures which are
specifically tailor made for a particular patient.

1) Common general measures

a) Try to maintain a regular daily rhythm and have a structured daily schedule

It is preferable for the patients developing dementia to do their daily chores—wake-up, go to toilet, exercise, have meals, take a nap in the afternoon, go for an evening walk etc. at the same time everyday. It is much easier for the patient to follow a regular daily schedule than to follow a varying schedule with his compromised cognitive abilities. A structured daily schedule keeps a person occupied and busy and makes the life more meaningful for him. A structured daily schedule may include, for example—Starting a day with morning walk, reading newspaper, getting ready, going to temple, going to nearby hospital for a voluntary service, resting in the afternoon after lunch, going for a religious group meeting or a recreational club in the evening and going to bed after watching a favorite TV program at night. This program may be written down in a form of time-table and may be displayed in the patient's room.

b) Try to remain in touch with the time, day, date, month, year.

Patients should have a big wall-clock and a calendar in their room so that they can constantly stay in touch with time. A clock which makes a loud beep-beep sound (Cuckoo-clock) at the end of every hour may be useful to keep the individual in touch with the time. Relatives may also indirectly remind the time to the patients during their communication. For example they may say “Grandpa its 12.00 noon, it's out lunch time, let's have lunch...”, “Uncle it's 6.00 in the evening, I have come to pick you up for the evening walk ...”, “Grandma, It's Wednesday today, I have to go for my music classes....”

c) Try to keep in touch with the recent events and new developments.

Glance through the newspaper, watch TV, listen to radio, and discuss the recent events with friends and relatives. Family members should also share gossip and rumors with the patients of dementia as they used to share it with him earlier, a few years ago.

d) Participate in various activities (religious activities, family functions, social events and celebrate birthday and marriage anniversary) and develop some extracurricular activities.

Go for a pilgrimage; go to a place of worship, attend ‘satsang groups’; go for a movie or an exhibition or ‘mela (fair)’ with your spouse, friends or family members. Attend wedding ceremonies and take part in sports competition or marathon-run organized for senior citizens. It has been
observed that good social network delays the onset of cognitive deficits. Develop some extracurricular activities such as singing, playing a musical instrument, drawing and painting, writing etc.

e) **Learn to operate new devices, gadgets, instruments.**

Though initially one may find it difficult to learn to operate new devices, gadgets and instruments, usually with practice one manages to learn operating new devices. Patients with dementia should make efforts to learn to operate mobile phones, remote controls and microwave ovens. In order to make the learning easy, one may mark certain buttons on the gadget with different color. For example, for preparing tea the patient has to keep a cup of water in the microwave and press only one button which is marked in red color. For talking to his friend, the patient has to press only two buttons – a speed dial button and button with a number 1 on it. These two buttons can be marked in red and green colors. These measures would reduce the patient’s dependence of the others and make him more self-reliant.

f) **Make provisions for easy and well supported mobility**

Accidental falls and fracture neck femur are not infrequent in patients of dementia. This can be prevented by observing certain precautions.

i) Have rough and non-skid tiles in the bathrooms and toilets.

ii) Make sure that the floor is dry and non-slippery.

iii) Keep the narrow corridors clear of any obstacles.

iv) Have a railing on one side of the broad corridor and on the stairways.

v) Use a tripod stick or a walker when necessary.

vi) Keep the corridors well lit.

g) **Avoid frequent changes in the arrangement of the furniture in the house.**

The brain stores the map of the house and therefore even at night one may be able to go around in the house without bumping into the furniture. Frequent changes in the arrangement of furniture in the house may cause inconvenience and may interfere with the mobility of the patients with dementia.

h) **Never retire, continue working**

It is very important to continue to work. Whenever possible continue to work full-time. If not possible work part-time, if even that is not possible work for a couple of hours daily. If one can’t
work independently due to cognitive deficits, work under supervision. Patients, who continue to work, continue to go to their factories or shops in spite of various deficits and difficulties, usually find life worth living. They have better self-esteem, better social life and feel that they are still a useful citizen of the society. People, who due to their deficits, stop working and just remain housebound, become lonely, fail to find meaning in life and do not find life worth living. They neglect their own hygiene and needs and also get neglected by their family members, relatives and friends.

i) Have small and frequent meals (Food and eating habits)

Due gradual atrophy of taste buds with the advancing age the elderly individuals may not be able to appreciate different tastes. The taste which is usually preserved till late life is the 'sweet' taste. Therefore they may prefer foods which are sugary. Small and frequent, freshly prepared meals (4-6 times a day) suits them well than one or two heavy meals. (For example: they can have a breakfast in the morning at 7.00 am, a fruit at around 10.00 am, light lunch in the afternoon at 1.00 pm, a cup of tea with biscuits at 4.00 pm, dinner at 7.00 pm and a scoop of ice cream at 10.00 pm before retiring to bed). A balanced diet having high protein contents, high fibers and low fat is generally preferred. Whenever required a help of a dietician may be sought. For edentulous patients a set of denture would be useful while for a very weak or bed-ridden elderly person one may mix and grind the food to a semisolid paste before feeding them.

j) Have easy-to-wear clothes

The healthy elderly individuals can wear all kinds of regular and fancy clothes as they like. But those who have neurological or cognitive deficits may not be able to do so due to dressing apraxia, poor coordination or difficulty in maintaining balance on one foot. They may require easy-to-wear clothes. Most of them may prefer a single one piece gown which is easy to put on and remove.

k) Take care of toiletry needs and habits

With advancing age urinary and bowel problems are common. One may have difficulty in passing urine due to an enlarged prostate or diarrhea and constipation. One may need appropriate medical or surgical measures for the same. A change in food habit, correcting dehydration or supervised use of laxatives may be required. For the elderly individuals who have stress incontinence or those who have lost their bowel bladder control in late stage of dementia one may have to use diapers and bathe and clean them from time to time.
I) Reduce or if possible stop alcohol intake and tobacco consumption

Excessive alcohol consumption and tobacco consumption may create problems such as falls and injuries under influence of alcohol and may interfere with cognitive functioning. Whenever possible one should try and reduce alcohol consumption or preferable stop it. Tobacco consumption has been identified as one of the risk factors for oral carcinomas and chronic obstructive pulmonary disease (COPD).

m) Avoid sleeping (short naps) during day time & sleeping pills at night

With the advancing age above 60, the sleep requirement decreases to 4-6 hours per day. If a person has habit of taking a couple of short naps of an hour or two during the day time he may not be able to fall asleep during night time. This may tempt him to take sleeping pills which may cause problems like partial dependence on the drug, hang-over the next morning, sun downer’s syndrome and cognitive impairment.

2) Measures which are specifically tailor made for a particular patient as per his deficits

There are some specific measure which one can take in order to help the patients having cognitive deficits, neurological deficits and behavioral and psychiatric symptoms associated with dementia.

These measures can be implemented

• at home with the help of relatives or community health workers, under supervision of a mental health professional,

• at the memory clinic or day-care-center with the help of trained staff or

• at the residential care facility where the patient is staying

a) Cognitive retraining

Cognitive retraining program may be utilized to help the patients having cognitive deficits in various areas. This may improve some of the cognitive skills of the patient and may prevent or at least slow down the further decline in cognitive abilities.

i) To improve the memory function: Patients may be asked to keep a diary and note down some of the important event of the day or any other matter which they would like to remember. If the patient has difficulty in remembering the names of his family members, he may be asked to make a family tree and write down the names of all the members of his family. When he has a difficulty in recalling someone’s name, he can refer to the family tree and recollect his name. One may consider putting boards at the entrance of every room in house such as ‘Kitchen’, ‘bed-room’,

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'bathroom' etc. Patients may be taught other methods to remember things like using mnemonics or using retrieval clues to remember certain things which patient wishes to remember. As an exercise to improve memory patient may be encouraged to play 'playing card memory game' or memory games on computers. Elderly person may repeat one and the same talk again and again every few minutes due to recent memory disturbances. It is important for the relatives & friends not to get irritated and not to humiliate the patient but to try and divert patient's attention and handle such situations more patiently & calmly.

ii) To improve visuo-spatial orientation: Patients having problems in visuo-spatial orientation may get lost while traveling. They may get into a bus going in the opposite direction, alight the bus a stop before or after the actual stop, may take right turn in stead of left etc. Depending on the actual type of difficulty, a therapist can escort the patient on his traveling route and help him to recognize and remember certain landmarks and clues which will help patient to travel independently. Patient may also be given a card with a map and directions on it to carry with him.
In case of difficulty in finding a way, he may show the card to a policeman or a shopkeeper and get the direction from them.

iii) To improve executive functions: Planning, organizing, decision making may be compromised in old age. Various games like Ludo, Chess, Draft, Chinese-checkers, puzzles, card-games etc. require these skills. Playing these games may help in improving executive functions. Similarly, from time to time, under supervision and guidance, they may be persuaded to plan and carry out some activities, (For example - a get-together or a camp, which may enhance their skills for executive functions).

b) Motor retraining

i) To improve speed, accuracy and coordination: Many of the computer games improve our speed and accuracy. Usually these games have different levels. At the novice-level or level-1, the game runs slow and as one develops the speed and accuracy; one can go at higher levels – the expert-level or level-5. Playing these games regularly may improve the speed, accuracy and coordination. Activities like drawing, painting, craft, sculpture-making etc. may also enhance these skills.

ii) To improve mobility: With the advancing age and especially due to motor or sensory neurological deficits the mobility is very much compromised. Static exercises like yoga and dynamic exercises like walking, jogging, aerobics may be utilized to improve mobility. Participating in outdoor games like volley-ball, hand-ball etc may also be very useful. When required one may use various prosthesis and walking devices to improve the mobility. In past good body massage was used to
rejuvenate the body and improve the mobility.

**c) Emotional retraining**

i) To improve the self-esteem and feelings of being a useful member of society: One of the most important parts of the rehabilitation program is to improve the self-esteem of the elderly individuals and make them feel that they are still very important and useful members of the society. Whenever appropriate, the family members should treat them as the heads of the family and seek their opinions, advice and guidance. Whenever possible they should be accompanying the family members for outings. They may be given some responsibilities according to their interest and abilities.

ii) To improve challenging behavior: Occasionally elderly individuals may show childish behavior or disinhibited behavior. One may have to deal appropriately using principles of behavior therapy in these kinds of situations.

(For example, if an elderly lady demands a candy-floss and insists on eating it on the road while walking, it may create an embarrassing situation for the accompanying family member. In this kind of situation one may allow her to buy a candy-floss provided she is willing to take it home and then eat it. One may have to deal little firmly at times to ensure a socially acceptable behavior. Similarly, if a grandfather starts changing his clothes in front of everyone or comes out of bathroom without a towel wrapped around his waist, one may have to be little vigilant and take appropriate measures to prevent disinhibited behavior).

Similarly elderly individuals may accuse relatives or maids/ servants in the house of stealing things when they are unable to find their belongings. In such situations, do not get upset and offended, but help him to find his lost belonging.

iii) To improve adverse attitudes of family members & to provide support to family members: Some family members may be overprotective and may not allow the elderly individual in the family to do anything by themselves. On the other hand some family members may be overcritical and keep on condemning the elderly without realizing that the unusual behavior is not intentional but is due to cognitive deficits. In such situations, counseling the family members is very essential for the effective implementation of the rehabilitation program.

**V) Residential care facility, Daycare center, Psychiatric Intensive Care Unit (PsylCU), Home assisted care and Self-help groups.**
A) Residential care facility

As mentioned earlier, some of the senior citizens, who are unable to lead an independent life in their own homes, may require residential care facility. Senior citizens having dementia may also require hospitalization or residential care facility when they develop delirium and behavioral and psychological symptoms associated with dementia (BPSD). Frequently, these patients may have to be restrained and require sedatives and tranquilizers which sometimes may further worsen their situation. In order to provide better facilities to elderly patients and to those who require short-term or long-term hospitalization or institutionalization it is desirable to have good residential care facilities. Elderly individuals and patients having dementia may not be very comfortable in the hospital-type of set-up. Within few days of admission they would demand discharge and insist on going back home, even though, at home they will have to be all by themselves. The serious & monotonous atmosphere of the hospital would make them dull and gloomy. So it is essential to change the hospital-type set-up and create a home-like environment in the residential care facility. Here, one will not find the reception desk, the registration counter and accounts office at the entrance. Nor one will find the staff in hospital uniform or white coats. There will be no wards with hospital cots covered with white bed-sheets and green curtains on the window. In a well planned residential care facility, one will find a group of elderly people sitting on a comfortable sofa-set in a drawing room enjoying their favorite show on television or a couple of them preparing some food in the kitchen and serving it to others sitting in the dinning room. People will address each other by their first name in an informal manner without the prefix of Dr., Sister or Sir - “Smita, please come here” or “Sanjay, How are you doing today?” Each individual in a long-term hospitalization facility will have a self-contained room to himself in a bungalow with a common kitchen and a drawing room. Depending on the need a residential care facility may have 6-7 such bungalows accommodating about 9-10 patients in each of them.

Cognitive enhancers (Donepezil, Rivastigmine, Galantamine etc.) and psychotropic medications may be sparingly used in the residential care facility. If a patient gets agitated or restless, instead of sedating him or tranquilizing him, he may be pacified using behavioral techniques in a non-threatening environment. Of course, all these facilities may not be complementary, at gratis. But if one is well insured than the individual or his relatives may have to born only about 10% of the total cost of the treatment; rest is taken care of by the government and the insurance companies.

B) Daycare center

Daycare center serves the same purpose in elderly which the school serves in children. To enjoy
the day-care center facility, offered at the residential care facility, it may not be necessary to stay there. The facility can offer a bus service which picks-up the elderly individuals from their home in the morning and brings them to the daycare center. Occupational therapists, physiotherapists, and counselors will take classes for them. They will make them sing songs and recite poems; will read-out stories to them and give them lessons in drawing, painting and craft. Senior citizens will also receive a sumptuous afternoon meal and supervised dose of medication. At the end of the day the bus will leave them back home with their families.

C) Psychiatric Intensive Care Unit (PsICU)

Along with these facilities the residential care may also have Psychiatric Intensive Care Unit (PsICU), and rooms for terminally ill patients who are bedridden. Even these patients are not supposed to spend their 24 hours in the bed waiting for their last breath. Like any other patients they wake-up in the morning, have their breakfast on a dining table in a sitting position with some assistance from the staff, then they are wheeled to the bathroom, where a special crane lifts them and puts them in a bathtub for a nice warm bath. After the morning chores they also receive their individual exercise and recreational activities during the day, before they retire to bed.

D) Home assisted care

For those individuals who can not visit the day-care center, community health professionals will pay home visits to provide the necessary help to the patients and probably more to their relatives.

E) Self-help groups

A group of senior citizens can start a self-help group. This group, like other self-help groups, can meet on regular basis and help the other senior citizens and organize various activities for them on a regular basis.

VI) Special issues

A) Marriage, divorce, live-in relationship etc.

Even senior citizens have right to get married if they are single or have lost their spouse; they have a right to ask for divorce if they are unable to happily stay together; and they also have a right to enter into a live-in relationship. As the needs of the elderly population increases, one may have to have marriage bureaus for them and special counseling centers and courts to deal with divorce applications filed by them. The changing norms of lifestyle will apply to them as well and they may prefer live-in relationship and the necessary provisions for the same.

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B) Foster families

The concept of foster family may work both the ways for senior citizens. Either they may adopt a needy young individuals or a couple and provide them accommodation, food and financial assistance in lieu of physical and nursing care provided by them or the young and working couple may adopt the elderly individuals or a couple and provide them accommodation, food and financial help in lieu of house keeping and childcare provided to their children by the elderly individuals.

C) Legal will, advance directives etc.

Making will or giving advance directives about ‘artificial sustenance of life’ or carrying out certain religious ceremonies after their death are some of the issues which gets importance at this stage of life. Discussion at an individual level or in group may be very helpful for the clarity on these issues.

D) Security

**DO’S**

1. Ensure all doors & windows have proper iron grills and lock.
2. Look through the magic eye before opening the door.
3. Use a safety latch to allow only partial opening of the door.
4. If possible keep a dog.
5. Always go out in a group for evening / morning walk.
6. Install a burglar alarm in your house and connect it with your neighbor’s house.
7. Intimate particulars of your servant as well as tenant to the police.
8. Keep vital telephone numbers handy for emergency.
9. Inform your nearest PCR (Police Control Room) van and neighbors if you are suspicious of someone.
10. Ensure you know the particulars of plumbers, electricians etc. before allowing them entry into the house.
12. Be in touch with the beat police officer.
13. In case of casual domestic help, ensure at least two confirmed references of prior employment.
   - Check the details of person who introduces/refers the servant.
   - Ask for name and address of telephone number of his relatives or his previous place of work.
   - Keep photograph & finger prints of servant.
   - Keep an eye on visitors of your servant.
• Contact your area Police Station for assistance in servant verification.

DON'TS
1. Don't keep valuables at home.
2. Don't boast of your prosperity to anyone.
3. Don't make an ostentatious display of cash and jewellery.
4. Don't trust strangers and don't open the door to unidentified people.
5. Don't ignore any suspicious incident. Inform the police.
6. Don't let your servant have access to your cupboards or safe.
7. Don't be a recluse, keep socializing.
8. Don't allow visitors to stay with the servant.

VII) Rehabilitative measures at society level
A) Special provisions for accommodation

In many countries government have special provisions for providing accommodation to needy senior citizens either on individual basis or on group basis. In UK, the government provides free group accommodations and financial assistance to senior citizens.

B) Special provisions to enhance mobility and for transport

To facilitate the mobility and journey of senior citizens special amenities should be made available on the road, on the station, at the super-market at the movie theatre etc. Some seats may be reserved in the buses and trains for elderly individuals; there may be separate queues at the ticket windows and elevators & escalators at the shopping centers and movie theatres. One may have a rope trains so that the senior citizens can reach the temple on the mountain.

C) Financial assistance, pension, dole, tax-rebates

Financial assistance in various forms such as pension, dole, tax-rebate, soft loans, special interest rates and investment plans etc. may be provided to improve the quality of life of our needy elderly individuals.

Section 80DDB of the income tax act allows a medical expense deduction of up to Rs.40,000 from the taxable income of patients with dementia. The maximum deduction permissible is Rs.60,000 in the case of patients aged 65 years and above. If the patient is not an income tax assessee but is the dependent of a caregiver who is an assessee, the caregiver can claim the deduction. To be eligible for the deduction, the level of disability resultant from the dementia should be at least 40%.

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D) Special provisions for recreational activities—'Nana-Nani Parks' 'Senior Citizen's Club' or 'Senior Citizen's Forum', mobile libraries.

The city of Mumbai has two beautiful parks called 'Nana-Nani Parks' and exclusive clubs for recreational activities for elderly individuals. Similarly groups or forums to address the pertinent issues and grievances of elderly should be in place. An NGO in Mumbai provides a mobile library service for the senior citizens.

One can also consider organizing Mr. Senior Citizen and Mrs. Senior Citizen competition. In this competition, they do not have to walk the ramp in designer's clothes but depending on their age, level of independence and activities in which they are involved they can be awarded the title of Mr. or Mrs. Senior Citizen and felicitated. They can be role-models for the other senior citizens.

E) Special courses and correspondence courses

A religious group runs correspondence courses on various aspects of religion and many senior citizens have enrolled their names for these courses. On registration for a particular course, one receives the course module and an exam paper. One is expected to go through the module, answer the exam and send it for evaluation. On passing all the modules the student receives a certificate.

VIII) References:


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IX) Resources

A) List of journals related to geriatric mental health care
   i. Clinical Geriatrics
   ii. Clinical Gerontologist
   iii. Geriatrics
   iv. Geriatrics & Aging Online
   v. Gerontology
   vi. Gerontology and Geriatrics
   vii. Journal of Aging and Health
viii. Journal of Applied Gerontology
ix. Journal of Gerontology
x. Journal of Mental Health and Aging
xi. Psychology and Aging
xii. The Gerontologist

iii) List of Evidence-based geriatric care books
1) Drug Prescribing for Older Adults: An Evidence Based Approach. Rosanne M. Leipzig, ed.,
5) Handbook of Pain Relief in Older Adults: An Evidence-Based Approach. F. Michael Gloth Ed.
6) Practicing Evidence-based Geriatrics. Sharon Straus, David Sackett BMJ Publishing Group,
   1999.

C) List of the groups, associations, institutes & research centers working in the field of
   geriatric mental health
1) Indian Association of Geriatric Mental Health
2) Aging Clinical Research Center, Stanford University School of Medicine
3) Alzheimers.com
4) Alzheimer Europe
5) Alzheimer’s Disease International
6) Alzheimer Italia
7) Alzheimer Society of Alberta
8) Alzheimer Society, Canada
9) Alzheimer Society of Ottawa-Carleton
10) Alzheimer Society Romania
11) Alzheimer’s Association Australia
12) Alzheimer’s Association of Australia
13) Alzheimer’s Association of South Australia
14) Alzheimer’s Association of Tasmania
15) Alzheimer's Association Victoria, Australia
16) Alzheimer's Association, New South Wales
17) Alzheimer's Association, U.S.
18) Alzheimer's Disease Society, UK
19) Alzheimer Disease Research Center (ADRC)
20) Alzheimer's Center, Stanford/VA
21) Alzheimer Page, Washington University, St. Louis
22) Alzheimer Research Forum
23) The Alzheimer Research Forum
24) Alzheimer Web
25) American Association for Geriatric Psychiatry
26) American Society on Aging
27) Association France Alzheimer
28) Alzheimer's Disease Research at Mass. General Hospital
29) Institute for Brain Aging and Dementia, University of California, Irvine
30) Institute of Gerontology, Wayne State University
31) LewyNet, Nottingham Medical School
32) Michigan Alzheimer's Disease Research Center
33) National Institute on Aging, U.S.
34) National Ageing Research Institute, U.S.
35) University Alzheimer Center, Case Western Reserve University

X) Appendix

A) List of homes and rehabilitation centers for senior citizens
1) Directory of Old Age Homes in India, Research and Development Division, Help-Age India, 1995

OLD AGE HOME DIRECTORY

Help Age India's Directory of Old Age Homes in India (2002). Old Age Home directory provides comprehensive information on 1012 old age homes in India. For copies of this directory, kindly send Rs.65/- as handling charges (By DD/MO only in favor of Help Age India, New Delhi. Cheques from Delhi are acceptable). If you need the contact details of homes in any city or state, the same would be sent by post/e-mail free of cost. Address: Research & Strategic Development Department HelpAge India C-14, Qutab Institutional Area, New Delhi 110016.
B) List of the various organizations working for senior citizens

1) Website for the list of NGOs working in India: http://www.ngosindia.com

C) SENIOR CITIZEN SECURITY CELL

For example: The senior citizen security cell of Delhi.

The Senior Citizen Security Cell was set up on June 22nd, 2004 under the orders of CP/Delhi.

Objectives: The main objective of the cell is to coordinate, monitor and advise the area police regarding the security and safety of the Senior Citizens.

Location: It is located on 1st Floor, Police Headquarters, M.S.O. Building, I. P. Estate, New Delhi.

Supervision: It is working under the supervision of Additional Commissioner of Police Crime, Delhi.

Telephone Nos.: Direct: 23490233 (Tele-Fax) PHQ Exchange: 23490010/4336