

# MEMORY CLINIC GUIDELINES



GOVT. OF KERALA  
DEPT. OF SOCIAL JUSTICE  
KERALA STATE  
INITIATIVE ON DEMENTIA (KSID)



## ARDSI GUIDELINES FOR ESTABLISHING MEMORY CLINICS



## PREFACE

The core principle underlying these guidelines is multidisciplinary team working aimed at a better quality service for people with dementia. Diagnosis of dementia has significant implications on everyone involved. However, dementia is largely unrecognised and undiagnosed in our country. Even when diagnosed, the services they receive are scanty. Memory Clinics are proposed to address the service gap to some extent. We hope these guidelines will help those who are interested in developing Memory Clinics which are multidisciplinary teams which aim to help and support the person with dementia and their family, right from the onset of symptoms to the advanced stages.

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This is only a beginning and we hope with more information and deliberations we can take this initiative further and we expect anyone with ideas and suggestions on this matter to get in touch with us.

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## **ARDSI GUIDELINES FOR ESTABLISHING MEMORY CLINICS**

### **1. Background**

These guidelines are to help establish Memory Clinics in any hospital setting and are not intended to be prescriptive in anyway. They need to be adapted depending on the service setting and resources available. These guidelines are formulated based on the extensive experience ARDSI has in working with people who have dementia, their relatives and other caregivers, dementia experts and professionals.

### **2. Why Memory Clinics?**

Assessment of people with dementia requires much more than a consultation which happens in an outpatient clinic. Memory clinics are not ordinary outpatient clinics where a neurologist or a psychiatrist manages patients with dementia. Memory clinics are much more than that. Memory Clinic consists of a multidisciplinary team which assess and manage patients with dementia on a long term basis.

Dementia is a condition with no curative treatment at the moment. The treatment focus currently is on alleviating the symptoms and distress associated with it. Dementia is not a diagnosis which can be made following a brief assessment in a busy outpatient department. Once the diagnosis is made following a comprehensive assessment, the details of the condition need to be explained to the caregivers. They need regular inputs in the form of medication,

psycho education, counselling and support which a routine outpatient clinic cannot offer. This explains why our traditional outpatient evaluation is not suitable for dementia patients. Hence the need for a multidisciplinary Memory Clinic team.

### **3. What does the Memory Clinic offer which an outpatient clinic cannot?**

1. An expert assessment of memory problems. 2. A multidisciplinary approach- medical (doctor) nursing, psychosocial (social worker/ psychologist etc) 3. Dedicated time for the family which a normal outpatient clinic cannot offer 4. Objective assessment of memory, behaviour, ADL etc 5. Better record keeping, audit and follow up. In essence, a better quality of expert care.

### **4. Who leads the team?**

A neurologist or psychiatrist is ideally placed to lead the team. If there are geriatricians available they are well placed as well. If none of them are available, physician with a special interest in dementia can step in. The team leader should have the abilities and skills to deal with the psychosocial challenges associated with dementia and the willingness to look beyond a medical model.

### **5. Who are the other team members in a Memory Clinic?**

In addition to the medical specialist, the Memory Clinic should also have a nurse and a social worker/psychologist. This need to be considered as the basic minimum staff composition of the Memory Clinic which can be expanded depending upon available resources.

In a well-developed setting with adequate resources eg. tertiary care teaching centre; a fairly large team comprising of a neurologist, psychiatrist, geriatrician, nurses, social workers, psychologists, neuropsychologist, physiotherapist, occupational therapist, speech and language therapist, dietician, trainees etc may be possible; but in reality there may only be a very few centres where establishment of such a team is practical or possible. However, working collaboratively with other departments in the hospital will increase the effectiveness of the service.

It is practical to start a weekly clinic on a specific day of the week at the same location and to follow fixed working hours. The frequency may be increased depending upon demand and resources.

### **6. Memory Clinics as Service of excellence**

There should be an objective assessment of the course and progression of illness. Families see this specialist service as a source to seek answers to their questions about dementia which have risen over several consultations when facing many challenges dealing with the person who has

dementia. Hence the Memory Clinic should strive to be a service of excellence for this patient group.

## **7. Process of assessment of a new patient in the clinic**

The specialist takes a history, does a cognitive assessment and performs a physical examination. If the assessment is done by postgraduate or junior doctors or a non-specialist doctor, the diagnosis and plan need to be agreed by the Consultant. Many patients reach the Memory Clinic after several consultations with various doctors and several investigations done. It is the responsibility of the Memory Clinic to review the investigations and treatment undergone so far, so that investigations are not repeated unnecessarily. Based on the assessment, appropriate investigations are arranged for, diagnosis made and medication plan decided and psychosocial management formulated.

The assessment includes detailed history taking, cognitive assessment and physical examination. The patient with suspected dementia may not be able to give a proper history. This means the history has to be taken from the family member which adds to the time of consultation.

A proforma which covers socio demographic details, clinical history, personal and family history, mental status, activities of daily living, behavioural and psychological symptoms etc may be used so that there is uniformity in assessment by all team members and this will serve as a document to refer upon during follow ups. Eg. ARDSI Memory Clinic proforma. Physical examination helps in diagnosis and to manage co-morbidity and the findings need to be documented in the proforma.

## **8. Cognitive and other assessments**

Cognitive examination is essential to determine the degree of impairment which is crucial to counsel the family. This also helps to assess the progress of disease during follow ups especially when the patient is on medications for dementia. MMSE (Mini Mental State Examination) is now copyrighted and should not be used without permission and payment. Commonly used current instruments include MOCA (Montreal Cognitive Assessment), ACE 111, m-ACE (Addenbrooke's Cognitive Examination).

Teams can decide upon routine use of instruments for regular assessment of Activities of Daily Living, neuropsychiatric symptoms etc. Eg. Barthel Index of Activities of Daily Living, Neuropsychiatric Inventory. Whatever instrument they choose to use, copyright issues need to be confirmed.

Diagnosis should be made based on accepted classificatory systems (eg. ICD-10 by WHO). Guidelines for dementia management should be followed. Once diagnosis is made this has to be explained to the family and what the implications are. This would require more than one session and is an ongoing process.

### **9. What are the common features associated with dementia, a Memory Clinic has to address?**

Cognitive symptoms, Difficulties with ADL (Activities of Daily Living), Behavioural problems, Psychological symptoms, Psychiatric symptoms, Co existing physical problems, Co existing mental health problems, Caregiver issues, Social and financial problems.

### **10. Medications**

The medical specialist prescribes and monitors medications. Medications commonly used in the Memory Clinic include cholinesterase inhibitors, memantine, antipsychotics, antidepressants and anxiolytics. Appropriate guidelines need to be used when medications are used especially antipsychotics, considering their serious side effects. It is recognised; there definitely would be a group of patients with severely challenging behaviours attending a specialist service like memory Clinic, in whom medications like antipsychotics may need to be used. Any such decisions need to be made in consultation with the families explaining the desired effects and possible side effects.

### **11. Inputs by the multidisciplinary team**

Nurses can coordinate the service (take a lead in record keeping, appointments etc). Many questions families ask relate to activities of daily living like eating, drinking, toileting etc which the nursing member of the team can satisfactorily address.

In addition to prescription of medications, it is the responsibility of the Memory Clinic staff to suggest behavioural and psychosocial interventions for symptoms associated with dementia. Usual symptoms include repetitive speech and behaviour, irritability, wandering, aggression, abusiveness, sexual inappropriateness etc. Psychiatric symptoms like delusions and hallucinations may also be present. The social worker/psychologist can take a lead in advising the families on these issues. This is time consuming as well. Hence it becomes important to design the service in such a way to meet these aims.

Though during the initial phases of team development, the medical specialist takes a lead in the assessment, as other team members become experienced they can undertake history taking, mental status examination and cognitive assessment under specialist supervision.

## **12. Follow ups**

Medications need to be regularly reviewed by the medical specialist. In addition to the cognitive assessment there should be periodic assessment of the neuropsychiatry symptoms and activities of daily living which the nurse or the social worker can do with some training and supervision by the specialist.

## **13. Access to other services**

If the team is led by a non-psychiatrist, there should be easy access to inputs by psychiatrist as majority of patients with dementia also have co existing mental health problems or behavioural and psychological symptoms.

Difficult to diagnose dementia/ rare causes of dementia-If there is no neurologist in the team, there should be easy access for referral to neurologist especially when needed.

Patients with dementia may need referral to other services. Some patients may need detailed neuropsychological assessment for confirmation of diagnosis and access to such services should be explored. They may also require referrals to Speech and language Therapy, Physiotherapy, Dietician etc.

To provide a better quality of patient experience when accessing services for investigations or treatment, the Memory Clinic should try to establish good working relationships with these services and educate the staff working there on the specific care and communication needs of people with dementia.

## **14. Caregiver stress, depression, anxiety and other mental health needs**

This is a major problem in dementia care and the Memory Clinic should be able to offer assessment and support for caregivers as well. There should be a system in place to identify their individual psychosocial and mental health needs and to provide appropriate support and service.

## **15. Information leaflets, brochures and caregiver manuals**

Memory clinics should provide families with dementia related information leaflets, brochures and caregiver manuals. However this should not be a replacement to counselling and psycho education of families.

## **16. Providing information about services; families of people with dementia can access**

There should be a directory of information about local services for dementia care and support which the Memory Clinic compiles.

## **17. Alternative sources of staff members**

At the first instance there should be a collaborative approach by different departments in ensuring the availability of social workers and psychologists. There might be such professionals already working with various teams whose time may be used for the Memory Clinic. As this is not a daily service, time may be spared for this service. As the service develops dedicated staff to the service should be considered.

Use of staff from outside the hospital- There are several health and social service schemes which the Kerala government and local governmental organisations run at the community level. Eg. Vayomitram. It has to be explored how the social workers or other staff from these projects could be trained to work as community link workers. One model would be, community workers attending the clinic and identifying any service needs which they can address in the community.

Close collaboration with District Mental Health Teams and Palliative services will be extremely useful.

## **18. Record keeping**

There should be proper record keeping regarding all patients attending the clinic. This is essential as the dementia journey is one which lasts for an average of around 8 to 10 years and it will be helpful for the team and the family to have the details ready. Record keeping will also help to improve the quality of services.

Depending upon local systems, decisions need to be made regarding where these records would be stored, to minimise misplacement and ensure easy access.

## **19. Audits**

Periodic audits are recommended to improve the quality of services. Eg. auditing the use of choline esterase inhibitors, auditing whether good practice guidelines are being followed when prescribing antipsychotic medications, auditing whether caregivers are satisfied with information provided by the clinic, auditing the extend of collaborative work with outside agencies etc.

## **20. Research**

Over the course of time, once the clinic is established, the team can consider initiating locally relevant research projects with close involvement of the hospital administration and ethics committee.

## **21. Networking with other Memory clinics**

As similar work will be done in other centres it will be beneficial to establish a network among different Memory Clinic teams so that good practice could be shared, guidelines could be formulated and training programmes planned.

## **22. Training**

Memory Clinic may also take a lead role in training in dementia assessment and care. Training programmes can be conducted for medical and nursing students, students of other health related professions, postgraduates in medicine and psychiatry, nurses, caregivers etc. Clinical posting for medical and nursing and postgraduate doctors should be ensured.

Awareness programmes in the community may also be planned.

## **23. Role of ARDSI**

ARDSI can play a role in facilitating the networking of memory clinics across the State, assist in formulation of guidelines, provide information leaflets and brochures, provide information of existing dementia services, assist with audit and research, awareness programmes and also make use of the existing National Dementia Helpline.