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AN BORD SLÁINTE LÁR TÍRE  
MIDLAND HEALTH BOARD

**Consultation Process with Staff  
within the Midland Health Board on  
the Needs of Older People with Dementia.**

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**Commissioned by  
The Working Group on Dementia  
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## **Executive Summary**

The following report was commissioned by the working group on dementia in August 2002, in order to obtain an overview of what staff perceived as the most pressing needs for delivery of a quality service, and what they saw as some possible solutions to the current difficulties.

A series of focus groups were run over the course of two months, consulting staff from both residential and community care settings.

A list of the needs identified and difficulties most commonly encountered/perceived by staff is given below.

### **Current needs/ Difficulties encountered**

- Inadequate facilities in residential care settings.
- Respite care available often inappropriate for people with dementia.
- Lack of suitable day-care facilities.
- All staff identified training as a major need. A list of areas where training was requested is given in the main body of the report.
- Confusion over availability of housing grants for making necessary changes/improvements to homes.
- Difficulties safely managing a person with dementia in the acute hospital setting.
- Lack of information about the person with dementia was raised as a issue by a number of disciplines:
  - Care attendants felt they did not have adequate information on individual dementia patients when they were admitted.
  - Catering staff felt they did not have adequate information on eating patterns of patients.
  - Nursing staff feel that inadequate assessments prior to admission to residential care mean they do not have adequate information.

- Home Helps also felt they often did not have adequate information on the people they worked with.
- Long waiting times to see a neurologist. Some confusion within the community setting as to the responsibility of giving a formal diagnosis of dementia.
- In some cases, a lack of co-ordination between services, e.g. CPN and PHN, may lead to duplication of work.
- Transfer of people from the community to residential care can be very distressing for family members, often because they are unsure of what to expect or to what extent they can still be involved in the care of a loved one.
- There is no community worker dedicated specifically for supporting people with dementia and their families.
- Inadequate information available for people in the community on dementia.
- Inadequate supports for carers of people with dementia in the community.
- Medical back-up identified as problematic in all care centres except psychiatry for older age in St. Loman's.
- High levels of stress amongst staff caring for a person with dementia – it was suggested training would help alleviate this problem.
- Transport.

The recommendations for change and possible solutions identified by staff have been categorised into long-term solutions and short-term solutions. Some problems identified have both short-term suggestions to ease the current situation and long-term suggestions to ensure maximum efficiency and quality in the future. All are listed below. A list of the recommendations staff felt were highest priority are also given.

## **Recommendations for change – Long-term solutions**

- Building of dementia specific units, attached to current care centres.
- Building of facilities to improve occupational therapy available to patients in Shaen Hospital.
- Need for staff to be more aware of special needs of person with dementia.
- Home respite service to be implemented.
- Similar facilities to the day hospital run by Psychiatry for Later Life in Portlaoise in the other three counties of the Board's area.
- A social worker for older persons needed.
- Additional information and education for families of people with dementia.
  - linked with provision of 'one-stop shops' suggested in the Board's communication strategy.
- A network of support services for carers of people with dementia
  - developing closer links with voluntary groups
  - innovative approaches to helping carers cope with stress
  - counselling services etc.
- Increase medical back-up available to care centres.
- Investigation whether the FAS mini-bus scheme currently being run in Longford would be feasible elsewhere in the Board.
- Identification of training needs of GPs in terms of dementia, and determining the boundaries of responsibility of the GP in relation to the person with dementia.
- Further research into the effects of ageism and how it can best be combated.
- Investigate the feasibility of a case manager to improve co-ordination of services.
- Additional staff in all areas.

## Recommendations for change – Short-term solutions

- Development of a training package, which could be rolled out to all staff working with people with dementia within the Board.
- Distribution of available material e.g. DSIDC Newsletter to ensure staff can keep up-to-date with current news and research.
- Subvention of additional respite beds in the Dementia Specific Unit in Laurel Lodge, Longford. Similar beds would need to be subvented in Laois/Offaly.
- More co-ordinated approach to application for housing grants and definition of this area of responsibility.
- A focus on changes in both residential and community settings to help reduce the number of acute hospital admissions (e.g. flexible mealtimes and availability of finger food and drinks throughout the day in residential care, increased home supports).
- Formalised information-sharing structures for care attendants.
  - The use of the carer diary, published by the Alzheimer Society, which could be used to increase the amount of knowledge available on a patients behaviour patterns, like and dislikes etc. when the patients is first admitted.
  - Formal reporting sessions with both nurses and care attendants each morning and evening in all care centres.
- Formalised information-sharing structures for catering staff on daily nutritional intake of dementia patients.
- Development of an integrated, multi-disciplinary, assessment/referral form.
- Defining responsibility for the diagnosis of dementia and development of guidelines for informing families of diagnosis.
- Formal guidelines for the type of information and encouragement for involvement to be given to family members on the transfer of a loved one from the home to a residential care setting in all care centres.
- Working in partnership with the Alzheimer society to increase distribution of their recently published information packs for carers.
- Provision of rummage rooms/rummage boxes in all care centres.

### **Prioritised recommendations for change**

- Localised dementia specific units
- Staff education and training
- Better communication between disciplines to provide more information on the patient to all staff working with them.
- More activities for dementia patients, more input from Occupational Therapists.
- More staff
- Social Worker for the elderly
- More information for families and carers. More encouragement for families to be involved with the care of the patient.
- More regular assessments
- A co-ordinated approach to the care of the person with dementia, including more interaction between statutory and voluntary agencies.

## Introduction

For many years now, the prevalence of dementia has been slowly but steadily increasing, and this is likely to continue for many years to come.<sup>1</sup> Dementia is primarily a feature of the industrialised societies, where the population profile has undergone huge changes in the last 100 years, bringing a far greater proportion of people into the older age range. Dementia as a disability is characterised by: impaired memory, impaired ability to learn, impaired ability to reason, and high levels of stress.<sup>2</sup>

Stedman's Medical Dictionary defines dementia as: 'The loss, usually progressive, of cognitive and intellectual functions, without impairment of perception and consciousness; caused by a variety of disorders ... but most commonly associated with structural brain disease. Characterised by disorientation, impaired memory, judgement and intellect ...'<sup>3</sup>

There are an estimated 30,000 people with dementia in Ireland. This number will most likely increase along with the ageing of the Irish population in the second decade of the next century<sup>4</sup>.

The recently published National Health Strategy acknowledged the need for additional services for people with dementia and the huge amount of work carried out by the NCAOP in their 1999 'Action Plan for Dementia' by identifying the need for "A clear framework for implementing the recommendations contained in reports on ... dementia is required".<sup>5</sup>

The 'Action Plan for Dementia' acknowledges the complexity and range of issues involved in the management of dementia, and emphasises the need for 'the development of co-ordinated, multi-layered, and well-resourced services that are responsive to the needs of people with dementia and their carers'. It also recognises that existing care arrangements in Ireland are fragmented, with the result that the benefits for people affected by the disease are likely to be below what might optimally be achieved.<sup>4</sup>

It has been recognised that it is often easy to forget the person with dementia in the search for optimal care strategies and efficiency in resource allocation. Kitwood outlined this phenomenon, and the need to change to a paradigm that place an emphasis on the 'PERSON with dementia', rather than the 'person with DEMENTIA' in his 1997 book 'Dementia Reconsidered; the person comes first'<sup>1</sup>. The majority of recently published policies reflect this paradigm, and providing patient centred services has been paramount in the National Health Strategy.

A similar approach is being taken in the UK, where the National Service Framework stresses the need for effective diagnosis, treatment and support for older people with dementia and their carers.<sup>6</sup>

The following report was commissioned by the working group on dementia in August 2002, in order to obtain an overview of what staff perceived as the most pressing needs for delivery of a quality service, and what they saw as some possible solutions to the current difficulties.

However, it must not be forgotten that while it is imperative to put the patient as the central focus of care, it is the personal motivation and dedication of staff working in the area that actually ensures patient centred care. Therefore, this report is not only about the needs of people with dementia, but about the needs of the health professionals who provide their care.

A general theme which emerged during this series of focus groups is that due to a long term lack of funding and resources in this area there is an endemic frustration and loss of motivation amongst staff, who often feel that they have spent years listening to reasons why they cannot have the support to provide the care they know their patients need. It is essential to maintain each care givers belief in what they do, and for them to appreciate that their work is both supported and respected by the Health Board. Unfortunately, in the current climate of lack of funding and resources which all health care professionals are familiar with, it is all too easy for an individual's motivation to be destroyed. In order for a quality dementia service to be available to the

population of the Midland Health Board Area, it is imperative that this degeneration is halted by the provision of the much needed services identified by staff.

The methodology section outlines the method of data collection and the staff consulted. The qualitative data collected on the services needed is outlined in the results section of this report. Not surprisingly, many of the issues identified can also be found in the vast body of literature available on dementia care today. However, in carrying out the consultation process it was possible to apply the general principles found in the literature to a more regional level, and to identify those issues which staff see as being most important. This section therefore contains not only areas identified as containing unmet need, but possible solutions to these gaps are also recorded and discussed.

The discussion section of this report attempts to bring together current national and international research findings and best practice with the principle findings of this report. In many areas, the two are extremely compatible, and where previous research has identified a possible solution to difficulties in service provision, these have been included in the recommendations section at the end of the report. The discussion mainly focuses on integrating the findings from the 1999 NCAOP 'Action Plan on Dementia' with the current research findings as this is the document recommended in the National Health Strategy.

While the report clearly identifies certain gaps and actions which need to be taken, some other areas that have been identified as needing more in depth analysis. Particularly, two areas where further consultation is needed emerged: consultation with carers and consultation with GPs.

The working group draw attention to the fact that while there is a focus on supporting and maintaining people with dementia in the community for as long as possible, the NCAOP have recommended that where there are severe and persistent dementia related behavioural problems, people be given specialist care in long stay units within psychiatry of old age services which are designated under the Mental Treatment Act.

## **Methodology**

In order to be able to fully explore the barriers staff currently face in providing a quality dementia service and gain insight into how staff felt these problems could be resolved, it was decided that a qualitative method of data collection would be used.

Focus groups are a form of group interview that capitalises on communication between research participants in order to generate data. They are a quick and convenient way to collect data from several people simultaneously, and are recognised as an effective technique for exploring the attitudes and needs of staff.<sup>15,16</sup> The idea behind the focus group method is that group processes can help people to explore and clarify their views in ways that would be less easily accessible in a one to one interview.<sup>17</sup>

Group discussion is particularly appropriate when the interviewer has a series of open ended questions and wishes to encourage research participants to explore the issues of importance to them. Because of these reasons, it was decided that a series of focus groups would be the most appropriate qualitative method for this piece of research.

The groups of staff to be consulted with were decided at a meeting of the working group. In line with recommendations for best practice in focus groups, line management and staff were consulted with separately. Dates and times for each of the groups were decided, after which various members of the working group took responsibility for inviting appropriate personnel to attend.

Representatives from each of the following groups were consulted with:

Nurses (both acute and longstay)

Care Attendants

Public Health Nurses

Paramedical Staff

Staff from psychiatry for older age (both residential and community)

Admission and Discharge Committees

Staff from both community care areas for each of the groups were consulted.

The focus groups were run over the course of two months. All focus groups were taped, and notes were taken on a flip chart during the session. Written consent was obtained for participation in the focus group and for the recording of the discussions (Appendix A). Information sheets were also handed out at the start of each group (Appendix B). Focus groups were then transcribed and the main points were broken down as seen in the results section.

## Results

### Facilities

As expected, the consultation process with staff identified a major lack of suitable facilities for people with dementia within the Midland Health Board Area. It was also identified by the admissions and discharge committee that the majority of referrals to them regarding people with dementia are looking for long term care, making this problem one of the most immediate. Below are listed the major problems/gaps in facilities in the long-stay settings, the acute, and the community, along with the suggestions for resolution from staff.

#### *Residential*

It was felt that none of the care centres have been designed to meet the needs of the dementia sufferer, and that numbers have grown so quickly there has been no time to change the environment to suit the patient.

*“... we’re forcing them to fit into an environment that we feel they should survive in, which is very unfair because their needs are so different from the needs of the other types of patients we are geared to care for”*

The specific problems identified with facilities in the long stay care settings were:

- No **safe area** for the person to wander freely. This was an issue strongly identified by both nurses and care attendants in both the long stay facilities and facilities for psychiatry for later life. It was felt that dementia patients find it both frustrating and frightening to be in a locked area. The open plan of many of the nursing homes have also been causing problems, e.g. patients mixing salt and sugar in the dining areas.
- The need for **single rooms** for people with dementia was also strongly identified. When a person comes in from a family setting to having to share a room with a large number of people, they can become even more

confused. It was felt that where a person with dementia can have their own space, ideally where they could have their own possessions, they become far less agitated, and are easier to manage.

- Need for a **separate facility** for dementia patients. It was felt that other residents often find the behaviour of the demented patients both disturbing and frightening. They also pose less of a threat for other patients if they have their own space (the safety risks a person with dementia may pose to other patients is explored more fully in the 'safety' section of this report).
- The need for **rummage rooms** was identified.
- Need for **recreational activities**.
- Need for **secure gardens**
- It was felt that a **snoozelen** was needed in every care centre. Staff training in how to introduce this resource to the hospital and to the patients was suggested as it was found in one care centre that the snoozelen was not used because some patients found it distressing.
- The **shower and toilet facilities** were identified as being problematic in most care centres as they were too small. More space is needed in order to be able to allow room for a second person to assist where needed. Showers particularly need room to have at least three people in the area together, a nurse, and attendant, and a client. Toilets currently pose a safety risk, where it would be impossible to safely lift a person should they fall. In fact, in St. Bridget's Ward, St Loman's hospital, commodes outside of the toilet themselves are most often used as it is not possible to assist a person in the small cubicles. This can be distressing for the patients as there is an unacceptable lack of privacy in doing this.
- The staff of the psychiatry for later life longstay facilities identified the very strong need for some sort of **family room** to be available for families when they come to visit a patient. Also the need for a palliative care room was identified.
- Several community workers felt that dementia patients who could not be accommodated in long-stay care centres due to lack of appropriate facilities were often placed in psychiatric care settings. It was felt that this

... was an inappropriate placing for the dementia sufferer, and was often upsetting for both the families and the patient.

**Recommendations for change:** Every focus group consulted with felt that a dementia specific unit, specifically designed to meet the needs of the dementia sufferer, was the best solution to the shortcomings outlined above. Although a minority of staff consulted felt the ideal would be to cater for dementia patients alongside other patients, as it would provide a high level of stimulation, the majority of participants felt that this had proven to be unsuccessful and that a separate unit was necessary. It was suggested that these units need to be small (4-6 bed) and localised, ideally attached to the current care centres.

Units could incorporate the features identified as lacking above, e.g. space for the person with dementia to wander (both inside and outside), single rooms, a rummage room, snoozelen and adequate shower and toilet facilities. It was also emphasised that it is essential that these units be located on ground level.

There is a need for appropriate staff to work in these units. Current staff who have expressed an interest in this area should be identified and trained accordingly.

It was suggested that suitable locations within the current care centres could be converted, rather than introducing greenfield sites in all areas. This would be of benefit to elderly relatives/spouses who would not be able to travel long distances to visit. It was felt that all staff should be consulted with as to the design of the units, and that the dementia specific units already built in the country should be visited to determine best practice.

This finding is in line with the thinking of the working group, and funding has already been secured by the Director of Nursing at St Vincent's Hospital, Mountmellick, for the conversion of one wing of the hospital to a dementia unit.

However, funding is the major barrier to the implementation of this recommendation. Time is the second major factor, as even were the funding available, these units would not be ready for use for several years. A shorter-term solution suggested during the consultation was the cordoning off of appropriate areas (ideally including a rummage room) in the current facilities for people with dementia. However, this suggestion would need to be examined more closely, as Rhiada house had attempted to do this in the past and found that there were huge cost implications in terms of appropriately trained staff to monitor the area.

It was felt that if there was a quiet area that dementia patients could be brought to, they would be less agitated, and it would give the other patients on the wards a break from them. Putting in extra alarm systems in all hospitals and providing enclosed garden areas were other suggestions for short term alleviation of the problems with current facilities.

Throughout the entire consultation process, the care centre repeatedly identified as being near crisis point in terms of being able to manage their dementia patients is Rhiada House in Tullamore. This care centre has a disproportionately large number of acutely confused patients, and is not sufficiently equipped or resourced to manage them appropriately. It would appear that it is only due to the dedication of current staff that a crisis situation has not yet occurred. Therefore, it is strongly recommended that whatever actions are taken to relieve the situation as a whole, that Rhiada house would be one of the first settings to receive the benefit of such changes.

### ***Shaen Hospital***

Because Shaen Hospital has always been a psychiatric facility for the elderly, it's needs are very different from those of other care centres, therefore they are dealt with separately here. Shaen also caters for the small minority of patients with dementia who have psychiatric symptoms or behavioural problems.

One need that is similar to all other care centres is for single rooms. Currently residents are sharing dormitory style wards, which, for the reasons outlined above, are not the ideal.

The major change needed in the facilities at Shaen is the improvement of the quality of life of residents through the extension of the occupational therapies available to them. Plans have already been drawn to convert some buildings already existing on the grounds into kitchen/living room type areas where residents can engage in activities, such as baking, cooking, washing that would be familiar to them. This situation would be especially ideal for dementia patients, who would have the freedom to wander in an environment (the buildings are located in the secure garden attached to the hospital) that would be familiar to them from their lives at home, helping them make the hospital a 'home from home'.

### ***Respite***

The need for suitable respite services was also strongly identified. Staff in the care centres identified the same problems with providing respite for people with dementia as with long-stay care (lack of area for wandering etc.). PHNs in Longford/Westmeath particularly identified a problem with being unable to place people referred to them due to the lack of appropriate respite care available for wanderers, particularly as many places have an open door policy.

Community care workers identified the suitability of respite as a major issue. Family concerns over dementia sufferers seeming to regress when admitted to care centres for respite were strongly identified. Some PHNs felt that the person regressed because they did not have enough stimulation in care centres. It was felt that staff who understood the specific needs of people with dementia were required, and that staffing levels should allow for the person with dementia to be dealt with on a one-to-one basis.

Also it was felt that some families had to wait too long before a person was placed in respite, and the carer could be 'burnt out' before respite was given.

**Recommendations for change:** It was suggested that if purpose built units were in place, these would be suitable places for respite. However, there may be a conflict of ideas here, as the current research suggests that ideally, dementia specific units should have as little disturbance to daily routine as possible, and that respite services should be located elsewhere.

A shorter term solution suggested was that another bed should be bought in the dementia specific unit in Laurel Lodge in Longford, and that similar beds be subvented in a dementia specific unit for Laois/Offaly.

A suggestion which was strongly recommended by a number of groups was that a home respite service would be implemented, where a person would be employed to come into the home and care for the person with dementia. This would effectively give the carer a break, while minimising the distress for the dementia patient.

### ***Day Care***

The majority of participants felt that current day care facilities were not suitable for people with dementia. One incident where there was a lack of suitable day care facilities led to a person being left at home with her carer indefinitely. This situation of critical unmet need was discussed, highlighting the need for suitable facilities in this area.

The day hospital facility run by psychiatry for later life in Portlaoise is currently running very well and is well utilised. However, there is a need for a similar service in the other three counties.

Some community workers expressed concern over the suggestion that there may be day care services provided on a part time basis. It was felt by two community workers that a part time service would not be adequate for the

needs of the areas, and that it may cause confusion to have a day service that is not available on a regular basis.

### ***Community***

Community workers identified how often the needs of the person with dementia are not being met in their own homes because of the layout/structure of the house. The major problem identified here was the time it takes to secure a housing grant. Often, the person in question has deceased by the time the housing grant is made available. Although this is not a problem restricted to dementia sufferers, it certainly affects their well-being, and the well-being of their carers.

**Recommendation for change:** Currently there seems to be confusion around how the housing grants work, and who's responsibility the grants are. A co-ordinated approach to these grants, with an agreement as to who is responsible for granting the funding requested is needed.

### ***Paramedical Staff***

In terms of facilities, paramedical staff reported having similar problems for all patients, they are around the areas of:

- Storage of equipment
- Delivery of equipment
- Transport of equipment
- Treatment space

### ***Acute***

Major difficulties with managing a dementia patient in the acute setting were identified. It was felt that acute wards were not designed to manage a person with dementia. Staffing on the wards does not allow for the constant supervision and attention that a person with dementia needs to be managed

correctly as there is only one nurse to manage the ward and care for the person with dementia.

It was also felt that the other acutely ill patients are often intimidated by the behaviour of the person with dementia. Therefore, not only are the needs of the person with dementia not being met, but neither are the needs of the other acute patients.

**Recommendations for change:** After considerable debate, it was felt that there were no clear solutions to the problem of the management of dementia patients in the acute setting. A dementia specific acute unit would not be utilised enough to justify the cost of staffing such a unit.

It was suggested that the appointment of an Alzheimer nurse in the acute setting may be helpful. This nurse could then carry out a full assessment of the needs of the dementia patient, and make recommendations to the ward staff on things they could do to make the care of the dementia patient more manageable/easier.

Another suggestion was for a PA system (personal assistant system) to be put in place for when a person with dementia has to be admitted to the acute setting.

Another suggestion was to have a safe area cordoned off in the acute ward where the person could wander safely. However, the feasibility of this was questioned.

Another approach to this problem was to do all that was possible to prevent acute admissions. It was felt that if dementia specific units were established, they may reduce the number of acute admissions, e.g. flexible mealtimes and the availability of finger food and drinks throughout the day may ensure that a patient would be properly hydrated and so remove the need for aggressive therapies such as the insertion of an IV line. Another preventive measure would be putting more home supports in, as it was felt that often acute

admissions are crisis admissions which occurred due to lack of support for the carer.

## **Assessments**

### ***Care attendants***

The care attendants felt they currently have no role to play in the assessment of the patient with dementia. In some care centres attendants have full access to assessment sheets, while in others they do not. It was felt by all that it would be very helpful to be able to see the patient notes. At the moment, they simply learn about the patient bit by bit. It was felt that as they spend a substantial amount of time with the patient, it would be helpful to them to have information surrounding:

- what stage of dementia the person is at, how progressive the dementia is.
- how the patient was at home prior to their arrival in the care centre, how it was felt the person might react to their new environment.
- whether the patient had previously shown any aggressive behaviours. Care attendants felt they were particularly open to being attacked or getting hit whilst carrying out duties such as feeding or dressing the patients.
- what their likes/dislikes were/are
- How families previously dealt with aggressive behaviours at home, tantrums etc.
- Background history of a patient, their family, work etc.

***“In order for a patient to get the best quality care, it is important for the person working with that patient to know as much about them as they possibly can ... if you are responsible for a patient, you need to be told about them”***

Catering staff also expressed a need for them to have ongoing reports of patient activities during to day. It was felt that if they were informed who had

eaten their evening meal and who hadn't, they would be able to prepare something else for them later in the day to try and get them to eat.

**Recommendation for change:** It was felt that each attendant should be given a full report of the assessments previously carried out on the patient prior to their arrival. It was also felt that there should be a care plan in place that the attendant could feed into, sharing their knowledge of the patient.

It was also suggested that the on-going reporting structure currently in place in Laurel Lodge and some of the MHB care centres, whereby both nurses and attendants receive a full report on each patient in the morning, and contribute to the evening report, should be followed in all care centres.

### ***Nurses***

A large majority of nurses felt that patients are not adequately assessed prior to admission. It was felt that it is imperative that adequate assessments be carried out prior to admission to determine what type of dementia a person has, and at what stage they are in order to be able to prepare for their admission. It was reported that often they would be told that a person has a mild dementia, when in fact they may be at an acute stage.

It was suggested that one reason for this apparent discrepancy could be that when a person is assessed at home, where everything is familiar to them, they can appear to be better than they actually are. Also, when being assessed at home, they are assessing the person as an individual. However, when you are bringing them into a unit, it is important to assess how they might react to the other patients who are there.

It was felt that adequate medical assessments are not carried out prior to admission. Often staff are not aware of other medical problems a person with dementia may have prior to admission.

Participants also suggested that sometimes a clear picture of the persons condition is not given as the priority is to get the person out of the home environment, and the family may be afraid that if the person is at too advanced a stage, they may be refused admission.

It was felt that different assessments are carried out by a wide range of staff, PHN, GPs etc., without one standard assessment procedure. It was also felt that the assessment tools used at the moment, e.g. Mini Mental and depression scores, do not give individual information needed, e.g. on behavioural problems or eating patterns.

Although a social report is carried out by the PHN, and this report contains much of the individual information needed by the care centres, it often does not arrive until 3 days after the person has been admitted.

However, it was also suggested that the assessments that are carried out at the moment are not taken into account when trying to decide where the person should be placed. At the moment, it would seem to be a case of where ever there is a bed, that is where the person is placed. Also, once a person is placed in a care centre, however inappropriate that care centre may turn out to be, it is very hard to change the placement.

**Recommendations for change:** It was suggested that the assessments prior to admission be carried out by a hospital based person. This person would then have the advantage of knowing what type of patients were in the unit already, and how this person would be able to assess how this person would be likely to interact with the others.

It was also suggested that a new assessment form be designed, one that could be used universally. It should incorporate information from the nurse, care attendant, carer, GP and PHN. A full social report should be given, as well as the reports carried out by dietician, physiotherapist, Speech and Language Therapist and Occupational Therpaists It was felt that there needs to be more sharing of information on assessments between the disciplines,

and that a multidisciplinary care plan may be the best way to achieve this. (A multidisciplinary assessment form is discussed in further detail in the 'transition/communication between services' section of this report)

### ***Acute***

Some nurses in the acute setting found that often the assessment tools are not readily available, in some instances they are accessible only through a doctor, and other times they are not kept in a designated place.

Some queries were raised as to the appropriateness of tools such as the Mini Mental State Examination and the MTS. Some staff felt that these tools, though they are the recognised international standard tools, were not sensitive to a patients needs, and were not appropriate to today's lifestyle.

**Recommendation for change:** That there be a standard protocol for the storage and accessibility of all assessment tools in all wards. That the appropriateness of other assessment tools be explored in conjunction with nurses who would often administer such tools.

### ***Community***

A lack of communication regarding the patients condition was felt to be a serious concern for home help workers. Home helps are not given access to any of the assessments carried out on the people they visit, and it was felt that this impeded the care the home help could give.

Public Health Nurses also identified lack of communication regarding previous assessments as a barrier to delivering a quality dementia service. Also, the lack of specific tools for assessing a person with dementia was identified by some as problematic.

**Recommendations for change:** it was suggested that firstly more communication between services regarding the assessments carried out by individual disciplines is needed. A standard assessment form that could be

given to all personnel working with the person with dementia should be designed.

### ***Community Psychiatric Nurses***

The two community psychiatric nurses consulted with felt that the assessment procedures they carry out are satisfactory, take into account all the services, and also include family members in the process.

### **Training**

All staff identified a need for training in dementia. It was felt that while everybody was doing their best for the person with dementia, sometimes they were unsure how to react to certain situations. The specific areas identified for training were:

- Understanding dementia
- Management of dementia - how to handle the patient, how to put them at their ease and make them comfortable with you.
- The management of aggressive behaviours – how to diffuse a potentially violent situation, to understand the underlying causes of aggression in the person with dementia.
- 'Self preservation training' – e.g. how to get out of grips without harm to yourself or the patient.
- What dementia is and how it affects the person
- On-going training that would include new developments in the area of dementia care, and current practice elsewhere.
- Training in the various assessment tools that are used.
- Training on dementia medication, the effects of various medications and any possible side effects or drugs with contraindications.
- Training/Education in what other services and entitlements are available to the elderly person with dementia, and how to refer to those services.

● Public Health Nurses expressed a need for training in nutritional needs of the person with dementia.

- Training in any alternative therapies or methods that could be beneficial.
- Training in counselling techniques.

It was felt that all training should be delivered on-site, as it was not always possible to release staff to attend off site training.

It was felt that both formal (home helps) and informal carers of people with dementia needed to be trained. It was suggested that the FAS training programme in Longford, which is currently being run to train people to be 'sitters' for people with dementia, be reviewed and if appropriate, expanded to all areas. This would ensure that a complete package of care would be delivered to carers.

### **Diagnosis**

Often families are left unsure as to the exact diagnosis a person has been given, and it was suggested that the reasons for this happening was the confusion of responsibilities amongst professionals. The importance of early diagnosis was stressed by many groups, as there are many lifestyle decisions that need to be made while the person is still lucid.

However, the admissions and discharge committee felt that there was no longer any problems with assessments and diagnosis since the appointment of the Consultant Psychiatrist for Later Life.

### ***Community***

Public Health Nurses identified problems in the area of diagnosis, where a person may be referred from the geriatrician, to the psychiatrist, to a neurologist who, because there are no neurology services within the board often has a waiting list of up to one year, without a formal diagnosis being

given to the family. It was felt that this delay in diagnosis was distressing for both the family and the patient.

However, PHNs did not feel that they should contribute to the diagnosis of a person. It was felt that diagnosis should come from the GP or the geriatrician. However, there were some reservations as to the tools GPs are currently using to make diagnoses as it was felt that not all GPs have the appropriate tools and training. However, it was felt that often people relate better to their GP, who they have already know and trust, and that a diagnosis coming from them would be easier to accept.

Some more concerns that were raised around the GP making the final diagnosis were that often, where a GP practice is full, there is a tendency for elderly people to be 'rushed through' (see Ageism/Stigmatisation section of this report). It was suggested that one way to overcome this problem was for the GP to conduct a home visit in order to carry out a full assessment and diagnosis. However, the feasibility of this solution is questionable.

**Recommendation for change:** That guidelines as to who would be responsible for the final diagnosis of 'dementia' are needed. Also that a further definition of the referral process is needed.

All GPs need to be given appropriate diagnosis tools and standard information packs.

### Transition/Communication between Services.

#### ***Community***

The PHNs in Longford/Westmeath identified a need for better communication with the Community Psychiatric Nurses (CPNs). It was felt that patients with medical needs were being discharged back into the community without the PHN being notified, or that both the CPN and PHN could be visiting the one client without being aware of each others visits.

## ***Residential***

Separate issues surrounding the transfer of people from the acute to longstay settings, and from the community to longstay setting were identified. One issue that is the same for both however was that all transfers into longstay should take place early in the day, and early in the week. This will give people time to settle into their new environment when there is a full compliment of staff. Further issues are dealt with separately.

### ***Transfer from the community***

That the transition into a longstay setting can be upsetting and difficult for both the patient and family was identified by many of the groups. Several attendants commented that families were often shocked, as they did not know what to expect, making the transition even more difficult.

The lack of appropriate assessments in the community was identified as a major problem for seamless transfer. This issue is fully explored in the 'assessments – nurses' section of the report.

**Recommendation for change:** That there be formal guidelines to ensure that families are included in the care of the person with dementia during their transition from the community, and encouraged to continue to take an active role in their life. (more information on this can be found in both the 'training' and the 'family knowledge' sections of this report)

### ***Transfer from the acute***

One of the current difficulties identified with transfer from the acute setting was the fact that doctors and nurses use separate transfer forms. This leads to time being wasted in reading through separate forms to determine the information needed. It was also felt that sometimes the transfer letter did not contain all the information needed.

Another issue which seems to be causing much frustration for the nursing staff of the care centres is that currently a patients drug prescription is written

on the transfer letter when they are discharged from the acute setting. In order to fill this prescription, staff must first find another medical doctor (most often a GP) to rewrite the prescription on a green script. This is time consuming, and often leads to a delay in patients getting the appropriate medication.

Again, a lack of information on the assessment forms posed a major barrier in seamless transfer. Often assessment would be more than 3 years old, or they would not have relevant details included. When a patient was being moved from one institution to another, often the family no longer had the most up-to-date information on the patient.

**Recommendation for change:** It was suggested that an integrated referral form be devised, one that could be used by all medical staff. Also, a formal mechanism for staff to liaise with both family members and staff who used to care for the patient to ensure that staff in the establishment the patient was being transferred to would have all the appropriate details regarding the patients physical and social needs.

It was also recommended that hospital doctors write out patient prescriptions on a green script and that there be a standard drug chart between the acute setting and long stay.

### **Support Services**

***“It is essential to have the support services to put in place after an assessment is complete”***

Although most people would agree with the above statement, that the support services are often not there is clear from the quote below.

***“... information leaflets can be problematic, because the support services outlined in them aren’t always available”.***

Therefore, not only was it felt that the new support services outlined below are needed, but that it is vital to ensure that support services that should already been in place, are in fact available.

### ***Community***

A need which was strongly identified in many of the groups consulted was the need for a social worker for the elderly. It would appear that at one time there was at least one staff member in this post, but not in recent years. The PHNs especially identified this deficit in services as being a major loss. It is very frightening for families to be told that a family member has Alzheimers, and it is necessary to give them some security that there will be someone there to support them.

While PHNs also identified a need for training in the area of entitlements for older people with dementia, it was felt that as financial supports change so regularly, a CWO specifically for older persons would be the ideal solution. It was suggested that often carers are reluctant to look for financial support as they are afraid it may affect their medical cards or partners wages. A CWO for older persons would be available to make home visits and answer all questions families may have in relation to financial entitlements.

It was also suggested that some sort of alternative therapies could be made available to carers in order to help them de-stress. Stress was identified as having a major impact on the quality of life of carers, and the amount of care they feel able to provide. It was suggested that stress is often a major contributing factor to incidents of abuse, where a carer can physically strike the person in their care due to frustration, or the older person is left in a wet bed simply because the carer cannot face going in to them again. In order for carers to be able to continue their work, and to ensure that they are able to maintain an level of health to allow them to continue, a support service that would help them de-stress (e.g. aromatherapy) should be provided.

***“...because the carer is not getting the support they need, the safety of the person with dementia is being threatened”***

Another support that should be put in place for carers is counselling. It was felt that where a carer was given counselling from the very beginning, as soon as a diagnosis was made, this made it very much easier for them to cope with the progression of the illness and their own feelings towards it. At the moment there are no formal mechanisms in place to ensure that family members will receive counselling. These mechanisms need to be put in place and counselling services made available.

More needs within the community that were identified were:

- Need for home chiropody services
- Need for full time geriatrician
- Need for a night sitting service

### ***Residential***

The support most needed in the residential setting was a full time registrar. Medical back up is a major problem for all care centres except in psychiatry for older age in St. Loman's.

### **Family/Public Knowledge**

Although it was not possible to consult with carers of any of the general public during this consultation process, staff were able to express views on the current amount of knowledge families have due to the close working relations many staff have with families and carers. It was felt that there was a general lack of education around dementia.

### ***Community***

The impact of this lack of education/awareness was felt to be far reaching. Several groups (particularly community based staff) identified that a lack of

awareness can lead to abuse or bullying of the older person, e.g. leaving someone in bed for lengthy periods of time as a way of managing them safely.

The need for training in such areas as manual handling and continence care were also identified.

The need for a central point of information was also identified, where families could get a comprehensive package of information. Lack of information can lead to social isolation. It was the opinion of the majority of people consulted that the GP or other primary health care worker is often the first point of contact for someone who may be concerned about either themselves or a family member developing a dementia. However, it was also felt that the amount of information a GP could provide varied from practice to practice.

***“Sometimes the GPs have great information services, and sometimes they don’t”***

**Recommendations for Change:** It was felt that it is extremely important for families to have education around the acceptance of the disease, and that group meetings are the best way to achieve this. Often people do not have time to read information leaflets, and find having the opportunity to discuss any problems they might be having much more helpful. It was suggested that linking with voluntary agencies would be the best way of facilitating such meetings.

A need for all GPs to have standard information packs and procedures for dealing with people seeking help with suspected dementia.

### ***Residential***

It was expressed by some groups that families need to be encouraged more to become involved in the care of the person with dementia. It was felt that at the moment, because care centres are run very much to a routine, families may feel inhibited, or that they are in the way.

Another reason suggested for the currently low numbers of families involved in patient care was that often family members are uncomfortable or embarrassed by the patients behaviour because they do not understand the progression of the disease. A lack of awareness often leads families to think that their presence does not make a difference and that there's no point in coming.

While it is recognised that social interaction is very important for patients, even being taken on a trip down to the local shops, some families have raised the question of whether the Health Board are still responsible for the patient when a family member takes them out on a trip. Such questions as these need to be addressed in the initial information and training

**Recommendations for Change:** That families would be encouraged to take an active part in the care of the person with dementia from the first day of their admittance to the care centre. This should include information on the disease and it's progression, in order to prepare the families for future changes in the person, and to make them aware of the positive impact they can still have on the patients care.

### ***Psychiatric Services***

The psychiatry for later life service have a set protocol for helping families deal with a diagnosis of dementia. The diagnosis is talked through with both the patient and the carer, and financial implications, safety issues etc are discussed. There is liaison with the GP to ensure that they are aware of their role, and the families are put in contact with the Carers Association and the Alzheimer Society.

**Recommendation for change:** This set protocol of what a family needs to know, and what needs to be discussed with them unfortunately seem to be in place only for the psychiatric services. It would be ideal if this protocol could be adopted by all health care professionals dealing with people with dementia and their families.

## **Safety**

### ***Safety of the person with dementia***

#### ***Community***

The safety of the person with dementia can often be at risk from bullying. The problems around the carer bullying the patient due to frustration or lack of education and training is discussed in more detail in the 'Family/Public Knowledge – Community' and 'Support Services – Community' sections of this report. Suggestions for possible actions to reduce this risk are also discussed in these sections.

The fact that dementia sufferers need constant supervision often means that they are at risk in community settings where it is not possible to provide 24 hour supervision.

The dangers people with dementia present to both themselves and others before an official diagnosis is made, or in the early stages of the illness where often people try to hide what is happening to them were discussed.

Currently there is no official policy about health and safety issues in the community, and many health professionals felt that this needed to be addressed.

#### ***Care Centres***

As mentioned before, dementia patient often wander into other people's room, rummage in other lockers or try to get into bed with other patients. Often, the dementia patient is vulnerable to being hit by an exasperated or frightened fellow resident.

It was also pointed out that the person with dementia is extremely vulnerable to abuse. One staff member related an experience of a demented person being molested by another resident, and not being aware what was happening to her.

There are huge safety implications for a person in the wandering phase, where the care centre is not equipped for such people. There is a danger that they may wander outside of the centre onto the main road, or fall down the stairs.

### **Safety of Staff**

*“An incident ... it happened at a time when we didn't have psychiatric backup, it happened at the weekend, and really we were just left, we had to cope. The staff were ... absolutely terrified of him, he had a grip ... and it was around the neck he would go for ... It took four staff to handle him and on night duty that's nearly a full compliment of staff. So when you're trying to deal with him the other members are on their own ... with the result then that come Monday morning he had to be admitted to psychiatric care”.*

Stories such as the one above highlight the very real threat to the safety of staff that a dementia patient can present. Similar incidents have happened in most care centres, both private and MHB. Although there was a medical doctor who was contactable at the time of the above incident, he did not have the skills to know how to deal with the situation..

**Recommendation for change:** That there be emergency psychiatric backup for if a patient becomes aggressive. Perhaps an emergency phone service where staff can ring for advice on how to handle a patient.

### **Acute Setting**

It was felt that the safety of both patients and staff are threatened in the acute setting and staffing levels are not adequate and staff are not appropriately trained. There is no alarm system, so it is not always possible for staff to know where the dementia patient is, or whether they have wandered. Also, the many levels in acute hospitals mean that patients are at a high risk from falls.

### **Management**

It was suggested by some that there needs to be a clarification of roles and responsibilities, i.e. who's remit dementia patients fall under. It was felt that there is still a confusion of responsibility in some cases, especially where there are behavioural problems.

It was recommended that in order to ensure that a co-ordinated and integrated care package for each dementia referral, that a case manager be assigned for every dementia patient. It was felt that the PHN is currently filling this role in the community, but that to have a designated case worker would be the ideal.

### **Patient Centred Care**

Some issues around tools for providing more patient centred care were discussed. It was felt by many people in both the community and residential settings that visual aids would be of great benefit to the patients. It was also highlighted that dementia patients are very sensitive to their surroundings, reacting favourably when corridors or day rooms are painted bright, fresh colours rather than traditional hospital colours.

Another issue that was explored around whether care was patient centred, was whether there was room for patients to bring in their own belongings with them, perhaps even pieces of furniture. It was found that the majority of care

centres felt they did not have enough room for the patients to bring in personal belongings.

***“Can’t make it a home from home when they only have a little wardrobe and locker”.***

Although this is an issue that affects all residents of long stay care centres, it is particularly relevant to dementia patients who, although they often seem unaware of their immediate surrounding, are greatly upset and agitated to changes in their environment.

## **Transport**

### ***Day Care***

Problems with transport to day care facilities is not a new one, and is one that has been discussed in many different arena's. Again the problem arose during this consultation process, where situations have arisen where a person is accepted to day care, but cannot attend because of lack of transportation.

**Recommendation for change:** A scheme in Longford was discussed, where there is currently a mini-bus available specifically for Alzheimer patients. This bus is funded by FAS, and has a FAS trained attendant working on it as well to ensure patient safety. It was suggested that this scheme be further examined with a view to expanding it throughout the whole Health Board.

### ***Care Centres***

For many people wishing to visit spouses or family who are in long term care, transport is a very major problem. Many elderly spouses have to get taxi's to visit, which can cost anything up to €70 per visit.

### ***Shaen Hospital***

Transport is a major problem in Shaen, exacerbated by the isolated location of the hospital. Because it is not attached to any town, Shaen hospital would ideally need it's own mini-bus in order to be able to overcome difficulties with transport. Currently they have staff to run the bus, but finance is again a major issue in this area.

### **Staffing**

The need for extra staff in order to provide a quality service to people with dementia was identified in all areas. However, it was highlighted that not only did such staff need to be appropriately trained, but they also needed to have an interest in working with dementia sufferers. People who would be patient enough to coax them away from doing something that might be harmful, or who would be able to distract them from their agitated behaviours are the ideal. The cost of identifying and training such people was cited as a major barrier.

In a number of care centres, care attendants expressed a wish to be able to work more closely with the dementia patient, helping them with all their needs, not only with physical care.

**Recommendation for change:** That staff to work specifically with dementia patients be recruited both from external sources, and internally, from amongst both nursing and care attendant staff.

### **Supporting staff in the short term**

The majority of staff identified training in dementia as a major need.

Stress relief sessions for staff were also identified as a need. Stress and 'burn – out' were identified as major problems amongst staff when the dementia patient was at the wandering phase. It is at this phase that most investment in stress management for staff needs to be made.

Introducing a rota system, where staff would have an hour on and hour off looking after a person with dementia, as it can be extremely stressful.

Identifying staff with a specific interest in this area, and allowing them to work with dementia sufferers.

### **Ageism/Stigmatisation**

Many people identified ageism as a major barrier to people with dementia receiving a quality dementia service. Often older people would be left waiting a long time in out patients to be seen, or an older person would not be referred to the appropriate services as their dementia would be seen as simply 'a symptom of old age', and the possible benefits to be gained from the paramedical services are often overlooked.

It was felt that there is still a stigma attached to dementia, leading families to try and hide it as much as possible, from both neighbours and relations, which often leads to a delay in the appropriate services being put in place. Having links with psychiatric services sometimes increases the stigmatisation of the illness.

**Recommendations for change:** Unfortunately there is no easy solution to the widespread social phenomenon of ageism. Perhaps the only way to begin to combat this is to ensure that both health care professionals and the general

public are well informed as to the exact nature of dementia, and the benefits that can be achieved for people of all ages. This route of more information for all should also reduce the stigma attached to having a dementia.

### **Early Onset Dementia**

Although there seem to be very few cases of early onset dementia, it was identified as being a separate issue from senile dementia, and one that needs a separate service of it's own. There are currently no facilities for people with Early Onset Dementia, and often they are inappropriately placed in the elderly care setting.

**Recommendation for change:** That a survey be conducted to identify the number of people suffering from an Early Onset Dementia, and that suitable services for these people be identified and implemented.

### **Shaen Hospital**

Due to the fact that Shaen Hospital has always been a hospital for psychiatry for later life, many of the procedures and structures identified as being needed in other care centres are already in place in Shaen.

Therefore, it is recommended that Shaen be looked to as a model of best practice for many protocols and procedures, e.g. including the family in patient care, risk assessments carried out on all residents, use of visual aids etc.

## Summary of Recommendations

At the end of each focus group session, staff were asked to prioritise what they felt was most urgently needed. The following is a list of the recommendations staff felt were most important. A more in-depth analysis of the gaps in service identified and recommendations for improvements can be found in the body of the report.

- Localised **dementia specific units**
- Staff education and training
- Better communication between disciplines to provide more information on the patient to all staff working with them.
- More activities for dementia patients, more input from Occupational Therapists.
- More staff
- Social Worker for the elderly
- More information for families and carers. More encouragement for families to be involved with the care of the patient.
- More regular assessments
- A co-ordinated approach to the care of the person with dementia, including more interaction between statutory and voluntary agencies.

## **Discussion**

The concept of a Dementia Specific Unit, which was identified as the number one priority by the majority of groups, is not a new one. The need for this type of service arises mainly out of the recognition that many dementia patients are inappropriately placed in long stay settings. Many countries have been running such units for a number of years, and provide us with an excellent blueprint for the setting up of these services. Indeed there are a number of quality units in Ireland that warrant close examination. This recommendation is also identified in the 'Action Plan for Dementia' –

Recommendation Number 9: "We recommend that dementia-specific day care places be provided in each district or community care area in buildings suitable for people with dementia and with staff who are trained in the care of people with dementia."

However, there are many areas that will need to be examined in relation to this recommendation, e.g. what are the most suitable buildings for people with dementia? Should respite be offered in these centres? Are appropriately trained staff available? How many beds should be available in each unit?

The process of finding the best possible answers to all such questions will take time, and will involve working in partnership with many different professionals. Following this, application for adequate funding to begin the implementation phase will be the next step. Although this solution is neither quick nor easy, it is the solution that is most favoured by the majority of staff members currently working with people with dementia, and is strongly supported in the current literature. It is a long-term solution to a critical and growing problem, and if initiated now should provide a mainstay resource to ensure that a quality service will be available to the growing dementia population in Ireland today.

-Another prominent theme, which emerged in many different sections of the report, was the need for stronger community support services to decrease the number of crisis admissions to respite, to acute, and even admissions to longstay. It was recognised in 'An Action Plan for Dementia' that the state usually intervenes when family care is absent, or breaks down, but is less willing to offer practical support to ensure the continuation of family care in a complementary sense. This 'fire fighting' approach needs to be changed.

A criticism of this current study is that it did perhaps focus primarily on staff working in residential care, and did not give adequate attention to professionals working in the community. Certainly, a strong need for GPs to be included in any strategy for dementia was identified, and it is unfortunate that time and resource constraints did not allow for the inclusion of this group in this consultation process. The NCAOP Action Plan specifically states that "The action plan should be biased towards home care solutions". Therefore, although dementia specific units were identified as the number one priority by staff in the Midland Health Board, there is a need for a financial commitment to support home care solutions.

The identified need for early diagnosis and structured support following diagnosis would be closely linked to the GP services especially. Again, this is not a newly identified need, and is one of the needs for primary care outlined in Chapter 6 of the NCAOP 'Action Plan for Dementia'. A separate consultation would need to take place with GPs to determine their current knowledge and future training and information needs.

There are some excellent guides and research available on this area, one of the most recently published of the Bradford Dementia Good Practice Guides being dedicated solely to Dementia and Primary Care<sup>7</sup>. A recent research project carried out by the Sperrin Lake Trust in Northern Ireland<sup>8</sup> identified some of the many difficulties faced by GPs and other health professionals in making diagnoses and gives recommendations for possible solutions to these problems. The Alzheimer Society in Northern Ireland has also very recently published a set of guidelines for the diagnosis and management of dementia

within primary care<sup>9</sup>. A research article on the evaluation of a national training programme on dementia which was established in the UK in 1997 is also a valuable resource available<sup>19</sup>. Therefore, this report recommends that a structured approach be taken to determining the boundaries of responsibility of the GP in relation to the person with dementia, using available research based evidence and in consultation with the GPs themselves.

Many groups voiced a very strong need for a social worker for the elderly. Currently there are no dedicated older persons social workers operating in the Midland Health Board, a situation which was felt to be unacceptable.

Many of the community needs identified centred around needs in the Home Help service. Adequate dementia training was a priority need identified, as well as appropriate Garda clearance and reference checks for those staff working with such vulnerable people as dementia sufferers. The need for out of hours services was also identified, as often one of the most stressful times for a carer is during the night when a dementia patient can become very agitated and tend to wander. Many of these recommendations have been previously identified in the 'Report of the working group for review of the home help service in the Midland Health Board' in 1997<sup>10</sup>, and more recently in the 'Review of Home Help Service' in 2001<sup>11</sup>. A working group has been formed with a view to implementing the recommendations in these reports, and it is recommended that the dementia working group working closely with the home help working group.

While a need was identified to improve current community services, it was also recognised that traditional statutory routes alone would not meet the needs of people in the community. The need for partnership with voluntary services was identified, as well as some more innovative ideas for the support of carers. The provision of alternative therapies such as yoga and aromatherapy, specifically for carers to help them de-stress was suggested in a number of groups. Such innovative approaches to community supports are encouraged in the NCAOP dementia report, which states that "Innovation on the supply side will have to be matched by innovation on the demand side,

linked to new funding arrangements, if community services for people with dementia are to be expanded”.

The need for closer links with voluntary agencies and the service users themselves has also been identified in the MHB “Report on a Consultation Process with Carers”<sup>12</sup>. The Forum for Older People is identified as a key structure in helping to develop such links, and it is recommended this structure be utilised and expanded.

The identified need for more information is not a need limited to only dementia care. This need has been identified in a myriad of reports relating to nearly every aspect of the Health Services. One of the solutions to this problem, which is currently being explored in the Midland Health Board Communications Strategy, is the implementation of ‘One Stop Shops’. This concept, which is also recommended in the National Health Strategy, aims to provide a central information point where the public can find out about any area of the health services they need to know about. Another possible approach to relieving the lack of information is to work in conjunction with the Alzheimer Society, who have recently published a very comprehensive information pack for carers. It is recommended that the feasibility of working in partnership with the Alzheimer Society to help distribute these information packs be explored.

It has already been suggested that such improved education and information networks should help reduce the ageism and stigmatisation that often surrounds dementia. It has also been recognised that ageism needs to be challenged through strategies which enhance the independence and autonomy of older people<sup>18</sup>. However, before a meaningful strategy can be developed to combat the effects of ageism, further research is need in order to determine exactly how ageism is translated into action within the MHB and what areas are most effected.

The need for a more co-ordinated approach to the management of care for people with dementia has many influencing factors. Communication plays a large part in this need, with many areas identified where better communication is needed between disciplines. Again, GPs would have a major role to play as they are often the first point of contact, and therefore are in an ideal situation to refer people on to the most appropriate services. The role of the Admission and Discharge Committee is an important one for the co-ordination of services, and has had an impact in this area. However, an approach that was suggested during the consultation process, and which is supported in the literature, is the idea of appointing a care/case manager for each person with dementia.

An effective integrated system of care requires that there are clear, co-ordinated and definite routes into a range of community services<sup>13</sup>. This can be achieved by nominating a key worker who would have responsibility for co-ordinating fragmented systems of community care for people with dementia. An in depth analysis of the implementation process for establishing a case manager is discussed in section 6.4.1 of the NCAOP 'Action Plan for Dementia'. A pilot project which was established in the UK in 1998 to provide dedicated social support to complement the work of the two specialist care managers is another resource worth examining<sup>20</sup>. Currently a case manager pilot project is being run in the South West Area Health Board in Dublin. It is recommended that the feasibility of implementing such structures within the MHB be explored.

While the above solutions are essential to the building of a quality dementia service, they are longer term, and their effects will not be felt for some years to come. Some of the shorter term solutions, discussed below, should, if initiated help to immediately relieve pressure on staff and improve the quality of care being delivered to dementia patients.

In relation to the quality of life of the dementia patient, a number of possible improvements were suggested, including rummage rooms, rummage boxes and alternative methods of relaxation (e.g. alternative therapies). Such

initiatives as these would not only be enjoyable for the person with dementia, it would also help to relieve staff stress as patients should be less agitated and inclined to wander into more dangerous areas. Such ideas as these are closely linked with training needs, as the more staff understand about the needs of people with dementia, the more they will be able to initiate small changes that will help the person relax and enjoy their daily activities.

This recommendation is linked with the perceived need for dementia patients to have more occupations, ideally these would be initiated with the support of an occupational therapist. Whilst waiting for the resources and funding to be made available for adequate OT support for all care centres, training of current staff might help to relieve this situation.

A need that was strongly identified, and which has little or no resource implications was the need for more information about the person, their personal preferences, hobbies etc. The care assistants were the group who most strongly identified this as a need in order for them to be able to give a high standard of care. The first principle in the NCAOP report, that "Respect for the preferences and right of the person with dementia should be at the core of the action plan" strongly supports this approach to care. Therefore it is recommended that a framework be drawn up and implemented that ensures all staff have the means of accessing information on the person in their care, either through personal files or meetings with family and other staff who have cared for the person. Another possible solution could be to encourage the use of the carer diary, recently launched by the Alzheimer Society. This would then give staff a more comprehensive idea of patients deterioration and behaviour patterns when they are admitted to an acute setting.

An increased use of the carer diary should also be improve the problems identified by the nursing staff with assessments, e.g. that often the severity of the dementia is incorrectly diagnosed. The diary should reduce the amount of errors in diagnosis between moderate and severe dementia as it will give professionals a very clear picture of the behaviour patterns of the person with dementia, and while someone may often appear very lucid during an

assessment visit, it is their families and main care givers who are in the best position to provide an accurate account of a persons dementia.

In relation to education and training, there are numerous training courses being run in dementia, and it is advised to link with these courses to ensure a comprehensive training package is delivered. The Dementia Services Information and Development Centre (DSIDC)<sup>14</sup> are currently delivering workshop and study days for all staff throughout the country. They also hold an Extra Mural Course in Dementia Care for Care Attendants and Home Helps. Some of these workshop days have already been made available to staff members in the MHB. However, training having been identified as being a very real need for all staff, it is suggested that linking with organisations such as DSIDC and the Alzheimer Society would be of great benefit. It may also be necessary to continue to develop additional modules around other areas identified e.g. medicines

Again, great use could be made of the services offered by DSIDC on keeping interested staff updated on current research and developments in Dementia Care. The DSIDC newsletter should be circulated to all staff working with people with dementia, and perhaps a travelling library, again relying on the resources already available at the DSICD. A mailing list of all staff working with people with dementia would need to be compiled.

In conclusion, although it may not be possible to implement all of the many findings and recommendations in this report, it is imperative that some action be taken to relieve the current situation. Many reports have been written regarding the needs of people with dementia, and the ideal services that should be provided. However, in order to ensure a quality dementia service, and if staff are to continue providing care and working in this area, positive action must be taken by the Board to relieve current working conditions.

Therefore, an Action Plan outlining the implementation of some of the recommendations will need to be compiled, and where appropriate, funding applied for.

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## CONSENT FORM FOR FOCUS GROUP PARTICIPANTS

### Consultation with staff on dementia needs

I have had the purpose of today's focus group session explained to me. I understand that we will be discussing areas relating to the needs of staff in delivering a quality dementia care service, and that the session will be recorded on audio tape. All information will be treated as confidential by the researchers, and I also agree not to discuss what other groups members say today outside of the groups.

I consent to take part in today's discussion and abide by the above conditions.

Signed/Initialled:

Date:



## **Consultation Process with Staff on Dementia Services within the Midland Health Board**

### **INFORMATION SHEET**

As part of the ongoing commitment by the Midland Health Board to improve the quality of services for people with dementia within the Health Board's area, the dementia working group was formed in February 2002 to investigate, implement and advise on both short-term and long-term solutions to the current problems faced by the dementia services.

It has been decided by this group to conduct a consultation process with all staff on their needs in relation to providing quality dementia care within the Midland Health Board. A series of focus groups are therefore being run in order to explore current gaps in service provision, to prioritise the needs identified, and to obtain suggestions for possible short-term and long-term solutions to the problems identified.

It is planned that a report of the findings from this process will be available by the end of September 2002, and that this report will be utilised by the working group to aid in service planning for 2003. All information collected at the focus groups will be kept strictly anonymous and confidential.

If you have any queries relating to this consultation process, feel free to contact Anna de Siún, Researcher for Older Persons, Clinical Audit and Research, at 0506 26044.

## **DEMENTIA PROJECT TEAM MEMBERS**

Liam O'Callaghan, Chair

Mary Carmody, Secretary to Project Team

Teresa Coman, CNM 1, St Vincent's Hospital

Anna De Suin, Researcher for Older Persons

Marian Delaney-Hynes, Co-Ordinator

Dr. Sabina Fahy, Consultant Psychiatrist, Psychiatry for Later Life

Margaret Feeney, Project Specialist for Older People

Grainne Flanagan, Senior Dietician, Community Dietetic Service

Margaret Lovell, Senior Physiotherapist

Mary Manning, Regional Practice Development Facilitator for Gerontology

Trevor McKay Morrissey, Regional Manager, Alzheimer Regional Office

Eddie McMonagle, Psychiatric Nurse

Dr. Micháel O'Cuill, Consultant Psychiatrist, Psychiatry for Later Life

Pat O'Doherty, Senior Speech & Language Therapist

Catherine O'Keeffe, Director of Nursing, St Vincent's Hospital

Caroline Whelan, Occupational Therapist for Mental Health



MIDLAND HEALTH BOARD

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5<sup>th</sup> May 2004

To: **The Chairman and Each Member of the Board**

Re: **Special Board Meeting**

Dear Member,

It was agreed at the monthly meeting held on 15<sup>th</sup> April 2004 that a special meeting of the Midland Health Board take place on:

**Friday 14<sup>th</sup> May 2004**  
**at 11.00 am**  
**in the Boardroom, Central Office, Arden Road, Tullamore**

This special meeting has been arranged to consider the Report commissioned by the Working Group on Dementia Midland Health Board.

Yours sincerely,

**Pat Gaughan**  
**Chief Executive Officer**

## MIDLAND HEALTH-BOARD DEMENTIA PLAN

### BACKGROUND.

Dementia is a syndrome that can result from a number of diseases that affect the brain. The World Health Organisation (WHO) definition is as follows:

*'Dementia is a syndrome due to disease in the brain, often of a chronic or progressive nature, in which there is an impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The cognitive impairments are commonly accompanied and occasionally preceded by deterioration in emotional control, social behaviour or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.'*

The incidence of dementia rises with age. As the population ages, and particularly as the number of people aged 80 years and over increases, there will be a significant increase in demand for dementia care.

### INTRODUCTION.

This report sets out the Midland Health Board services vision, values, strategy and priorities for the delivery of services for older people with dementia based on recommendations from both national and regional reports on dementia care.

- National Council on Ageing & Older People –Action Plan for Dementia 1999
- Action Plan for Older People Midland Health Board 1997 (currently being revised)
- Midland Health Board Dementia Report 2002.

### VISION, VALUES AND PRINCIPLES

The guiding principle of the MHB mission statement is one of promoting the health gain and social gain of its population in the four counties, Laois, Offaly, Longford, and Westmeath. The Board's strategic focus makes it clear how this should be achieved: "working with partner agencies, meeting the assessed care needs of older people living within the Board's area, which enables them to live as safe, fulfilling and independent lives as possible."

*"To achieve this aim the Board will work alongside older people and their carers to assess and meet individual need as required. It will also be proactive in the further development and improved delivery of service across the Board."*

Government policy is that older people should remain in their own homes for as long as possible and be supported in this choice (*The Years Ahead, 1988*). Therefore, it is vital to ensure that services evolve to match these aspirations and as far as possible anticipate future trends and demands. The development of services for older people must continue to be in line with the four goals' of the National Health Strategy Quality & Fairness (2001).

Within the national and local context, the strategic plan for dementia care will provide a basis for joint planning and collaborative working with partner agencies and other key stakeholders, including service users and carers. Key themes have emerged during consultation with relevant stakeholders in recent years within the Board's area. These include the range of services provided for older people and people with dementia, partnership working and staff training and development.

**The Priorities outlined in this report have been identified on the basis of the following;**

- Quality and Fairness – A Health System for you
- Action plan for Dementia. National Council for Ageing and Older People 1999
- Midland Health Board Action Plan for Older People 1997
- Demographic projections and prevalence of dementia
- Views of staff (as reported in Dementia Report Midland Health Board 2002)
- Consultation with older people, through the Royal Consultative Forum for Older People 2001
- Views of interest groups e.g. some service users, National Council on Ageing and Older People and carers of people with dementia.
- Evidence of what constitutes good practice e.g. in terms of a therapeutic physical environment and integrated care etc.

**What service users want:**

- Services that promote choice, independence, and that are appropriate to their needs both in the community and in residential care settings
- Innovative day services, which enable access to health promotion activities
- Integrated services from a well-trained and multi-skilled workforce
- Service Planning to be informed by user's views
- Respite care provided in a variety of settings
- Appropriate transport.
- Services which are accessible

**Key Challenges.**

- To provide a range of person-centred service delivery options, for people with dementia and their carers in appropriate environs.
- To ensure that diagnosis, early assessment and early intervention are an integral part of dementia care.
- To improve access to dementia care, particularly in rural and remote areas
- To destigmatise dementia and promote working in this specialised area of care

Dementia care cannot be viewed in isolation from other services for older people, The strategic direction for dementia care, therefore, must reflect the broader strategic policy context articulated in other strategy services for older people. The Board is currently auditing the implementation of, and reviewing the Action Plan for Older People.

**Vision of services in the future.**

- Enhanced range and quality of services
- Early diagnosis, appropriate assessment and early intervention for dementia.
- Services delivered in an appropriate setting
- Highly skilled workforce that delivers quality care.
- Appropriate support for carers.

## **Strategies to enable Older People's needs to be met.**

### **Assessment**

- Improved assessment.

### **Access**

- Improved access to a range of services.

### **Service delivery**

- An integrated approach to the delivery of dementia care services, across community, acute, residential and specialist settings.

### **Carers**

- Services that support carers.

### **Workforce development**

- Enhanced education and training for all staff who work with older people with dementia.

### **Partnerships**

- Enhanced partnerships and linkages in the provision of dementia care, across all health settings.

### **Desired outcomes**

1. High quality services provided in an appropriate setting.
2. Improved access to a range of support services for the carers.
3. Improved quality of life for people with dementia and their carers.
4. Improved health status for people with dementia and their carers.

### **Recent service developments which provide support to people with dementia and their carer's include-**

- Training of staff
- Improvement in the physical environment to make it more appropriate for dementia care e.g., sensory gardens, alarm and monitoring systems, one dementia specific unit (Mountmellick)
- Establishment of the Community Rehabilitation Units
- Admission & Discharge Committees
- Appointment of Carer Co-ordinators
- Appointment of Case Managers
- Training programmes to support carers in their caring roles
- Appointment of Consultants in Psychiatry for Later Life and multi-disciplinary teams
- Additional funding provided allowed for expansion of Home Help service
- Partnership approach with Alzheimer's Society, Carers Association in the provision of home care, day care and respite service
- Promoting healthy lifestyles among older people in the community e.g., Go For Life Programme and in the Board's care centres.
- Appointment of Activities staff in residential care settings creating stimulating environments for clients e.g. Arts in Care, Music Network and Physical Activity Programmes.
- Age Awareness training for staff and community groups
- Senior Help Line for older people

## POPULATION PROJECTIONS

As the number of people over 80 years is projected to increase steeply over the next twenty years, so will the numbers. In planning services for the future it is important to address these demographic factors and to ensure that services are flexible enough to accommodate these changes. In particular services will have to provide for a significant increase over the next 20 years in the number of older people with a range of physical disabilities and dementia.

(See appendix 1 for demography / estimated numbers)

## CURRENT SERVICE PROVISION

### MIDLAND HEALTH BOARD & PRIVATE NURSING HOME BED NUMBER

Name	Total No. Beds	Longstay Beds	Respite Beds	Rehab	Other
District Hospital, Abbeyleix	50	40	6	2	2 Hospice
St. Brigids Hospital, Shaen	62	60	2	-	
St. Vincent's Hospital, Mountmellick	158	129	7	4	6 Hospice 12 Young Disabled
Ely House, Birr	70	58	12	-	
Riada House, Tullamore	42	36	6	-	
Ofalia House, Edenderry	59	52	6	-	1 Hospice
St. Joseph's Longford	173	147	4	20	2
St. Mary's, Mullingar*	118	101	3	14	
St Vincents Athlone	76	63	8	4	1 Hospice
Loughloe House, Athlone	38	35	3	-	
St. Camillus, Killucan	1			-	
<b>TOTAL</b>	<b>(847)</b>	<b>(721)</b>	<b>(57)</b>	<b>(44)</b>	<b>(24)</b>
<b>Total Day Care Places</b>	<b>(326)</b>				
<b>NURSING HOME BEDS</b>	Offaly	Laois	Westmeath	Longford	<b>Total</b>
	265	77	330	195	<b>(867)</b>

### Respite Care

There are 57 respite places in the Board's care centres, but these are not always suitable to meet the needs of an individual with dementia. Staffing constraints and/or lack of training may prevent from caring for someone with complex needs. Two private nursing homes run a specialist planned respite and day care service for people with dementia. Other nursing homes may offer general respite or respite on an ad hoc basis if rooms become available short term, but this is unreliable and it makes forward planning difficult for carers. In order to ensure that carers have access to respite care as required, the Board will extend the availability of respite beds for all older people over 75 years. O Connor et al in 1998 estimated that 17% of older people are looked after by carers in the community. Applying this figure to the over 75 year population in the Board area being cared for in the community. The Board will require approximately 120 respite beds in order to provide an adequate respite service.

To look at possibilities of enhancing the quality of life for service users through the use of assistive technology, which can enable people to stay in their own homes or in specialist housing.

### **Home Care**

As a result of the Community Rehabilitation Service less older people need long term services. There are now six community rehabilitation units in operation, and it is planned to have another unit in Athlone operational by the end of 2004. The Community Rehabilitation Service, enables people to leave hospital more quickly –however this service only deals with people with dementia if they have a physical need for rehabilitation.

### **Home Help Service**

The Home Help service has received additional funding over the last number of years in response to the increasing number of older people at home and in need of support. However, the service needs to be greatly enhanced in order to meet current and future needs.

## **PRIORITIES FOR DEVELOPMENT:**

### **Capital Investment in Care Centres for Older People**

The Board's policy is that all care centers should provide a continuum of care, thereby meeting the needs of older people with a range of problems including dementia. This will require capital investment in all care centers.

### **Facilities**

The Board will enhance its care centers so that the physical environment is therapeutic for people with dementia.

### **Joint working and single assessment**

The Board's staff working with other agencies will develop and implement a single assessment instrument which takes account of all the health and special needs of people with dementia.

### **Care Management Framework**

The Board will continue to improve co-ordination of care through the case managers as recommended in the NCAOP Action Plan for Dementia care (1999). The appointment of case managers has improved co-ordination, cut down duplication and improved integration of services.

### **Day Services**

A Partnership approach to the provision of day care services for people with dementia will allow for effective resource allocation which avoids duplication of health and social services. The Board will continue its partnership with the Alzheimer Society and other non-statutory organisations in the provision of day care.

New and creative commissioning processes will continue to be developed in purchasing respite and day care in private nursing homes, ensuring at all times equity of access across the Board's region.

### **Staff Training and Skill Sharing**

The Board has provided a comprehensive educational awareness programme for staff to support them in their roles of caring for people with dementia. Eighty-six trainers will cascade training with the objective of training all staff who care for people with dementia.

### **Staffing Norms**

Currently staffing to patient ratios across the Care Centres varies. The Nursing & Midwifery Development Unit is currently carrying out work in relation to Nursing staff levels and skill mix.

### **Carers Support**

The Board will continue to improve the involvement and support of carers through:

- Carer networks, improved information, carers assessments
- Further dissemination of information packs specifically targeted towards carers of older people with dementia in partnership with Alzheimer Society. Continue to consult with carers by various mechanisms i.e. consultation fora, Consumer Panel's.
- Provision of training to enable carers to be more aware of issues.

### **Community links and outreach services**

The Board will further develop;

- Links and initiatives with housing agencies (Models of good practice in this respect have been examined)
- Links and initiatives with the non-statutory and voluntary sector
- Local community initiatives, Consumer Panels, Age Awareness programmes

### **Housing**

The Board will develop a range of accommodation for older people and develop services to meet needs as a result of increasing frailty and dementia, including the provision of 'smart' housing for older people and people with dementia.

### **Tackling Ageism**

The Board will continue to proof its policies with respect to ageism by training staff and seeking the views of consumer panels. The Board has already commenced this process and have held two consultation/training days for staff and non-statutory service providers involved in care of the elderly.

### **Health Promotion**

The Board will continue to promote healthy lifestyles in the community and in its care centres.

### **Complaints**

The Board will continue to analyse complaints with a view to learning how services can be improved.

### **Integrated Services**

The Board will work to further improve greater integration of housing, social and health services.

## **Funding**

Improvements for which we particularly need funds for are:

- Upgrading of facilities
- Improved staffing (all grades)
- Training of staff
- Further improvement of community services including day care services
- Improvement of respite care

The Board is currently costing these priorities and will submit detailed costings to the Department of Health and Children in order to meet the needs identified.

## Appendix 1.

Estimated number of persons with dementia by county: based on an application of Eurodem prevalence rates to population; (CSO Statistics 1996 & Eurodem)

County	Population of all ages	Females with Dementia	Males with dementia	Persons with dementia	% of all ages with dementia
LONGFORD	30,166	176	133	309	1.02%
LAOIS	52,945	249	210	459	0.87%
WESTMEATH	63,314	309	227	536	0.85%
OFFALY	59,117	274	222	496	0.84%
<b>TOTAL</b>	<b>205,542</b>	<b>1,008</b>	<b>792</b>	<b>1,800</b>	<b>3.58%</b>

## TOTAL POPULATION OVER 65 YEARS IN MHB (CSO 2002)

Age Group	Total	65-69 years	70-74 years	75-79 years	80-84 years	85 years and over
Longford	4264	1,227	1,008	959	620	450
Laoighis	6647	2,005	1,768	1,405	900	569
Offaly	7392	2,311	1,863	1,596	1,001	621
Westmeath	7898	2,382	2,018	1,725	1,067	706
<b>TOTAL</b>	<b>26,201</b>					