1 SUMMARY – Is small always good in dementia care?

Background to the assignment and approach

The number of elderly people is expected to increase enormously over the next few decades. Norwegian municipalities need to increase the number of care places. The challenges facing the municipalities will be to obtain sufficient, high-quality, adapted residential facilities. Residential schemes should provide good quality, tailored services and allow resources to be used efficiently. Buildings are often cumbersome, inflexible structures that will influence the lives of staff and residents for many decades to come. It is therefore vital for regulations and incentives to be in place to enable the development of good residential schemes for elderly with dementia.

This report describes and discusses a number of models for residential schemes for people with dementia, based on existing information and knowledge about ongoing projects. In addition, relevant recent research has been subject to a systematic review, to create an up to date database. The review has been published as a separate memorandum (SINTEF Memorandum 16). We have also described and visited numerous residential facilities and services (in Norway and abroad), and have facilitated interdisciplinary discussions about the consequences of these various models in terms of staffing, physical systems, service arrangements/operational philosophy and qualitative objectives. We have conducted interviews with unit managers and consultants in municipalities regarding their experiences with various housing schemes for the elderly and any strategies they have for developing new projects. In a separate research project, the Norwegian National Advisory Unit for Ageing and Health has conducted a survey of the municipalities' current provisions for people with dementia (Gjøra, 2015), and this has been brought into the discussions. In terms of financial considerations, we have used the reports The partial cost key for nursing and care: Analyses of unit costs, grades of coverage, expenses and user payments. SØF (Centre for Economic Research) Report no. 04/13, (Borge, 2013) and Resource utilisation and illnesses in dementia (REDIC) (Vossius, 2015), as well various other calculations. The issues that we wish to address in this report are complex. Physical solutions, service models and financing are separate research fields, but they are also factors that influence each other. This means that we have had to examine all three aspects at the same time, and look closely at how they affect each other. For this reason, an interdisciplinary research team was established. In addition, the were discussed in research workshops in Norway and a research workshop in the Nordic region.

Key facts about dementia

Dementia is an umbrella term describing a condition that is caused by various organic diseases, and is characterised by chronic and commonly irreversible cognitive impairment. The consequences of which are changes in social behaviour and increasing difficulties in performing day-to-day activities. The diseases that lead to dementia become more common as people get older. The proportion of elderly people in the population is increasing, therefore the number of people with dementia will also increase in the years ahead. We estimate that in 2013 there were about 78,000 people with dementia in Norway (Alzheimer Europe), and that in the year 2030 there will be more than 100,000 people with dementia, rising to almost 150,000 in 2040.

Various studies in Norwegian nursing homes show that about 80 per cent of the patients in Norwegian nursing homes have a dementia condition. Diseases that affect brain function cause dementia; however, over the last two decades there has been growing recognition that the clinical picture that defines dementia is not just a manifestation of the neuropathological changes in the brain. Dementia is also influenced by the personal psychology that an individual has developed through their life, together with the social environment around the person. By looking at the interaction between these factors, a better understanding of the phenomena associated with dementia may be provided, rather than one based on a purely medical understanding of the condition. Dementia is a progressive condition, with an increasing impairment of mental capacity. This means that the vast majority of sufferers become dependent on continual supervision, care and nursing during the course of the disease, and in the end, most will be dependent on some form of 24-hour support. In Norway, people with dementia are commonly given a place in an ordinary nursing home. Since the mid 1980s, efforts have been made to make physical provision that is better suited to people with dementia (smaller residential groups). Using Statistics Norway's prognoses for the population in 2040, the same incidence rate forecasts between 140,000 and 148,000 people with dementia. Some recent studies indicate that the future incidence rate of dementia will be somewhat lower than estimated, particularly in the oldest group. On the other hand, some factors indicate that life expectancy in the future has been underestimated, and that the number of elderly people in the oldest group will be higher than previously estimated.

Good for whom?

With regard to the quality of services offered to people with dementia, the most important figures are the users themselves, and their relatives. Questions that should be asked are: What are the physical and social surroundings that best help a person to cope and have a meaningful life? And at the same time are suitable for ensuring that the person receives sufficient care of the right kind in relation to their functional impairment and need for assistance? Originally, nursing homes often were designed according to a hospital model, with a focus on clinical needs and effective care. Over time, our knowledge about quality of life for the elderly and living with dementia diseases has helped to change this concept. The

view of the patient has generally also changed; patients are no longer 'only' patients, but unique individuals, residents and users. In line with this understanding, research and the development of theory and practice have contributed to a shift towards a more person-centred focus. Democracy and participation have been further emphasised in policy documents and guidelines – most recently in the 2020 Dementia plan. However, society in general is not necessarily best served by models and solutions that are only optimal when understood from a user's perspective. Solutions that cannot be funded or implemented from a financial perspective are not particularly sustainable. We must therefore look for solutions that use resources efficiently, and at the same time are experienced as good from the perspective of residents and staff.

What the literature review says

The literature review is relatively unambiguous and emphasises the need for a physical environment that supports a person-centred care system in which the key factors are autonomy, the sense of being at home, good social relationships and meaningful activity. Research emphasises that the social environment is at least as significant as the physical, but that the physical environment has an important role in terms of supporting and facilitating social relationships, interaction and movement. The results of research show (to somewhat varying degrees) effects in relation to a reduction in agitated behaviour, depression, etc. among patients. A number of authors emphasise the importance of the physical environment in person-centred care. They points out that it is important to design the physical environment around the needs to compensate for impairment, promote independence, reinforce identity, increase self-respect and making nursing easier for care staff and the family to work within and use.

What is small...?

However, in the literature or in the facilities that we visited, the definition of small does not come across as unambiguous. Small can include both physical and organisational concepts, and the two dimensions are not necessarily interlinked.

Organisation in small units

The case study and literature study both emphasise that one of the most important measures in terms of achieving more person-centred care is for the facility to be organised into small, manageable residential groups, which are serviced by a smaller number of permanent staff members who can get to know the residents. *"There is always one of us present, on 'lounge duty' – and the fact that we are there enables us to get to know the people and thereby avert conflicts by suggesting activities or taking other actions to prevent a situation from becoming critical. There is bound to be a degree of turbulence, since these people are here because they are suffering from a serious illness. But this allows us to 'nip things in the bud' and avoid agitated behaviour and frustration. We have become particularly good at interpreting signals. This is made easier for the simple reason that we know each and every one of them so well" (employee at secure unit).*

However, several municipalities state that they have had good experiences with bringing several residential units under the management of a single organisational body. This approach can help to increase the variety of services offered, and is thus a means towards the development of services that satisfy a greater number of individual choices and wishes. It is also a measure that can contribute towards more cost-optimal solutions. *"Variation and flexibility are keywords. People in serviced housing can be offered day care within a residential group in a nursing home. Someone living in serviced housing or at home can spend the night in a section of the nursing home if they experience a brief acute episode. A 'crisis bed' can be set up for one or two nights. These different types of service contribute to greater flexibility. It is beneficial for the unit manager to have responsibility for the entire package" (unit manager). In this way, an organisational unit can cover multiple residential facilities and have the flexibility to offer various 'packages' of care.*

Small physical factors can be discussed based on:

Size of the private quarters

The case study shows that there can be a direct incompatibility between having large private quarters and a residential group that is perceived as homely. Large private quarters are often serviced by long corridors, which make it harder for residents to feel that they are a part of the residential group. Many people with dementia need help and support if they are to participate in everyday activities; these tend to take place in the common areas, which must therefore be located close to the residents. However, if the residents are to have the feeling that they are at home, they need to have facilities such as private quarters, for which a minimum amount of space is required. In a Nordic context, Norway operates with the smallest private quarters. However, when private quarters are about 30 m2 including bathrooms, interviews with staff and relatives show that no one believes that such quarters need to be bigger for this target group. In fact, Hogeweyk in Holland goes even further in terms of reducing the *size of its private quarters. Fosslia Bosenter residential home has some similar small units with shared bathrooms, but does not consider the situation to be ideal. "The residents (and their relatives) do not want to move when they start to need more care. The rooms are not designed to accommodate aids like hospital beds, lifting equipment, etc. However, the common areas are extremely homely and cosy, and we have tried to build on this".* In Beim Goldknapp, there is a facility that is specially designed for the last phase of the disease, proximity to staff being the key factor in this facility. This includes an 'oasis' consisting of one large room for eight residents, and there is always a member of staff present.

Size of the residential groups

The size of the residential group is a key factor, and is regarded as the most important physical measure in terms of supporting person-centred care. For a number of years, Norway has therefore been dividing institutional departments into smaller groups. Research and accounts from staff confirm that this makes units quieter, and improves the lives of residents and staff. The size of residential groups dictates how many personnel should be allocated to them, which has an impact on costs. In Norway, we find groups of between 4 and 12 residents, and the literature study discusses units of up to 15 residents. The size of groups, which should be recommended also, depends on the target group for whom the facilities are being provided. For people who need 'standard' help, a minimum two members of staff should service the residential group during the day and two at night. This corresponds to multiple residential groups of about eight people. The national survey carried out in 2014 showed that the majority of municipalities have group sizes of eight residents. The facilities are organised as residential facilities or as institutions. Secure sheltered units are facilities designed for people who need a high level of personnel resources all the time, and who need extra protection. Several people express the view that it would be beneficial to have the option to divide the physical groups into even smaller units, this would provide extra protection for these groups. This case presentation illustrates that the 'homeliness' of the residential group is not just about the number of apartments grouped around a common area. The design of the common areas, the manner in which people get to the residential group and the manner in which daily tasks are facilitated all have an impact on the perception of the physical surroundings.

The size of the facility as a whole

There are many reasons for locating multiple residential groups within the same premises; these can include sharing resources for night services, and providing access to activities and specialised skills and services. On the other hand, there are also many arguments against bringing multiple units together. Stigmatisation and the perception of being put away in 'an institution' run contrary to political objectives for integration. People with dementia have recently begun to speak out more clearly with their own voices, expressing a desire to continue to participate in society. The case study contains examples of small communal residential schemes, located in ordinary residential areas, where the residents (accompanied by staff) can visit and make use of activity facilities and other services in the same way as other people do. The objections to this type of service centre on the resources needed at night and the lack of trained specialist staff. It has been demonstrated that the latter problem can be resolved if the residents register with the same GP, and if there is close cooperation with home services or other nursing homes. The use of resources at night is the remaining object, but this is not an inconsiderable objection.

The number of residential groups sharing the same premises, and the manner in which they are organised, affects the lives of the members of the residential groups to a lesser extent during the day. We find that the manner in which these residential groups are organised has a major effect on their access to outdoor areas and their opportunities to take part in activities other than those offered by the residential unit. Nor can we get away from the fact that large facilities are often constructed around an institutional culture, in which it is easy for the institution as a workplace to overshadow the fact that it is also the home of individual people. It is important to emphasise that there does not need to be a direct link between these factors, and Hogeweyk in the Netherlands exemplifies this. This facility offers a wide range of services, but its surroundings provide associations to a normal life. We believe that the Hogeweyk model has enabled us to start questioning our current methods of addressing the issue of large nursing homes. It has also led professionals to start a debate. Comparisons have been made with the old institutions dating back to the HPVU reform, which are held up as the worst possible examples. We believe that it is also useful to make comparisons with many of Norway's big, new and modern hospitals, which are perhaps an even less integrated. They also suffer from a lack of easy access to outside areas and different activities.

Organisation of service and culture of care

Physical surroundings can support good care, but they cannot guarantee it. Fundamental elements in new concepts and solutions are good service models. The services provided must attend to both the professional medical perspective and the social education perspective. It is therefore important to present and discuss new examples from a human resource perspective, training and the use of unskilled and volunteer workers to provide services. At De Hogeweyk, we can see that this is at a somewhat lower level than what we are used to in Norway. However, we can also find Norwegian examples, such as the Fosslia residential centre in Stjørdal, which demonstrate some of the same qualities, as well as providing good medical coverage and having a strong focus on dementia-related training. Relatives of Fosslia residents also express a high level of user satisfaction. However, this model requires some radical tailoring to adapt it to a more urban lifestyle if it is to be relevant to the lives of the elderly in urban settings. The trial projects being conducted by Oslo's nursing homes, such as those at Økern and Manglerud, are therefore of particular interest.

An operational economic perspective

An important dimension and an integral question in this assignment was the discussion of costs related to services for people with dementia. Confusion and insecurity are some of the reasons why we want to provide special accommodation and services for these people. Clinical symptoms and the need for services are progressive. Costs, service provision and the need for services are dimensions that are to some degree interlinked. In addition there are factors that also affect the need for services, particularly in the early phases of the illness. Relatives, volunteers, living arrangements and new technology

can be used in varying degrees. There is an enormous difference in the amount of resources needed by people who live outside an institution, and the amount needed by those who live inside one. The first place to look for any cost-saving measures must be in this gap. Municipalities describe various types of measures that can help improve the figures. A place in a nursing home is currently estimated to cost around NOK 1 million a year. If a resident could live in a facility lower down on the 'care scale', even for another six months, this would result in a huge cost savings. In the following section, we describe a range of measures that can affect costs and the need for institutions.

An option for volunteers/relatives to become involved in the care arrangements? – The experiences from Hogeweyk are difficult to transfer to Norwegian conditions, because we have a different volunteer culture. Nevertheless, experiences show that volunteers are also an important resource for many municipalities in Norway. *"We focus on getting relatives involved in the facility. They should feel welcome and know that they are regarded as an important resource".*

The development of new kinds of residential facilities: *– "There are many people living in this housing facility, who spend their entire day within this community, and it's clear that if they lived on their own, independently, their lives would be very different. I therefore imagine that it would be possible for people to live at home longer, if we have this kind of facility. Many people here are in the early stages of dementia." (unit manager of serviced housing facility)*

More day care services: *"Some people agree to day care for one day a week, and others for four days a week. I am in no doubt that this postpones their need to move to an institution and provides respite for the relatives during this period".*

Improving skills: *"The most important thing is probably to improve skills across the board. We use behaviour mapping as a method and try to understand where, when and why someone becomes agitated. We also keep medication to a minimum; people are often taking far too much medication when they come here. For this we rely very much on good medical assistance. We have a stable staff and low rate of sickness leave. (Total certified sickness leave is below 8 per cent)".*

Use of new technology*:* Economies of scale in terms of night-time services, patient alarms and key systems. It is not within the scope of this study to estimate a figure and place a value on the effect of these kinds of measures. Many of the municipalities we spoke to would like to see a more systematic evaluation of these types of experiences. There is a need for interdisciplinary studies that examine the care culture and physical environment alongside cost optimisation. There is also a need for further attempts to find measures and kinds of residential facilities that can support people with dementia and to verify their impact. This would enable the sharing of experiences, and ensure that what is built today also forms the building blocks of a strategy towards a sustainable provision of care in the future.

There are some restrictions in current regulations, that may be perceived as complicating the work of municipalities which are trying to think innovatively. However, we believe that the biggest challenge comes from the fact that the various agencies choose to consider things only from their own perspective. Innovation requires that everyone sees the whole picture, and to discuss facilities that are to be a workplace, a place of residence, a place that is attractive to visit and an establishment that can be operated as optimally as possible. We believe that if 'trials' are earmarked, this could make participation easier for all parties.

There needs to be a more systematic verification of the trials that have been conducted and incentive schemes that could support more ideas that are new and innovation. By innovation, we refer to the processes and solutions that include changes to the service culture, organisation of services, new buildings and the use of new technology. Verification is not just about measuring satisfaction, it requires explicit interdisciplinary research that measures the effect of the different measures against the various perspectives and targets that have been set. Do the residents go outside, are they peaceful, what does it cost to run, staff sickness leave, etc.