

**Services for People with Dementia
in Wales**

March 2003

Report No.2.

**Services for Younger People with
Dementia**

Dementia Services Development Centre Wales

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Executive Summary

This report from DSDC Wales is the second of a series of 'snap-shots' of service provision for people with dementia in Wales, arising from a Service Mapping project funded by the National Assembly for Wales. It focuses on analysis of information relating to services for younger people with dementia.

Based on an estimated prevalence rate of 67.2 per 100,000 in the 30-64 age group (Harvey et al. 1998) and using data from the 2001 Census we estimate that there are currently approximately 893 people suffering from young onset dementia in Wales.

While Alzheimer's Disease is the most common cause of dementia in the under 65 age group it only accounts for approximately 30% of the cases. There are a greater proportion of rarer dementias present in this population. These have different symptoms and prognosis and may be more difficult to recognise and diagnose for professionals not familiar with them.

The survey highlighted a dearth of provision for younger people with dementia. The relatively small numbers affected makes the provision of services outside centres of population difficult, and there is a great need for creative ways of providing the care that is required by some of those affected. There is a need for commissioners of services to consider how best to provide age appropriate services both in the community and in residential, nursing and hospital settings. The establishment of databases would seem to be an essential first step to assist in the identification of younger people with dementia and their health and social care needs. This could then contribute to

the demographic profile and be used by commissioners of services. We would recommend that other areas investigate the merits of establishing such a database. However, it must be recognised that even this relatively small first step needs to be resourced in terms of both computer facilities and staff time.

Throughout the production of this report we have encountered a wide variety of people who recognise the need to develop services for younger people with dementia and are eager to investigate and embrace new models of service provision.

We would recommend the development of a network to support those working in this area and to assist sharing of expertise and training resources. This would also facilitate the evaluation of new service models and their replication or modification to enable development in other areas across Wales.

1. 1. Background

1.1 The Dementia Services Development Centre Wales is a partnership between the University of Wales, Bangor and the Practice Development Unit (Mental Health Services for Older People), Cardiff & Vale NHS Trust, and forms part of the UK wide network of such centres. DSDC Wales has been operational since August 1999, providing information and resources for service providers and encouraging service development. The Centre also offers training and conducts research into dementia care.

1.2 Requests for information regarding services for people with dementia and their supporters are regularly received by DSDC Wales, and in November 1999 the National Assembly for Wales agreed to fund the establishment of a database to collect together as much information as possible on such services. This would serve to increase the information resource available to service providers, planners and commissioners.

1.3 The database has now been established, and enables detailed information on the whole range of services for people with dementia and their supporters to be collated. Like any database it is reliant on the information provided by service providers and this places limits on its accuracy and the comprehensiveness of its coverage. However, it is a dynamic electronically based system that will allow for responsiveness to service changes and developments. Now the framework is in place, there will be a continual endeavour to up-date the database and extend its coverage and usefulness.

1.4 The database allows an analysis of services by service type and by area of the country, and these analyses may prove useful in identifying areas of good practice as well as areas where there is a need for service development. Each analysis provides a snap-shot of services at a moment in time, which may enable changes in service provision to be tracked in years to come. The second in a series of such analyses has been undertaken on services for younger people with dementia in Wales and forms the subject of this report.

2. Service mapping project

2.1 The survey sample

The data on which this report is based comes from a postal survey of services for people with dementia in Wales conducted in early 2001. Key personnel from each care service were identified (usually the manager) and were invited by letter to complete a questionnaire. The survey consisted of a comprehensive questionnaire designed to gather information about several key areas including:

- • Demographic information on the service users with specific reference to people with dementia
- • The type of service currently provided
- • Operating details, including the various facilities offered
- • Staffing characteristics and staff training
- • Information relating to carers of people with dementia

2.2 In addition we have endeavoured to find information on the services for younger people with dementia which may not have been contacted or replied to the survey in 2001 or which have been established since that time.

3. 3. Definitions

3.1 Dementia

The World Health Organisation define dementia as:

‘A syndrome due to disease of the brain, usually 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 and motivation.

3.2 Young Onset Dementia

A person is normally considered to be suffering from a young onset dementia if they develop the illness when under age 65.

4. Prevalence of Young Onset Dementia

4.1 Prevalence Data

A number of studies have examined the prevalence of young onset dementia by review of medical case notes. These include Newens et al. (1993), McGonigal et al. (1993), Kokmen et al. (1989) and Schoenberg et al. (1985). The study which is currently accepted as providing the most comprehensive prevalence data is that of Harvey et al. (1998) which identified cases of young onset dementia in two London boroughs. A comprehensive methodology was used to attempt to identify every case of dementia which began before the affected person was aged 65 years and to establish a specific cause. This study suggested a prevalence rate of 67.2 cases per 100,000 at risk in the 30 – 64 years age group. The Alzheimer's Society use a prevalence rate of 1 case per 1,000 (100 cases per 100,000 at risk) in the 40 – 64 age group. To date there have been no studies of the prevalence of young onset dementia in Wales.

4.2 Estimated Prevalence of Young Onset Dementia in Wales

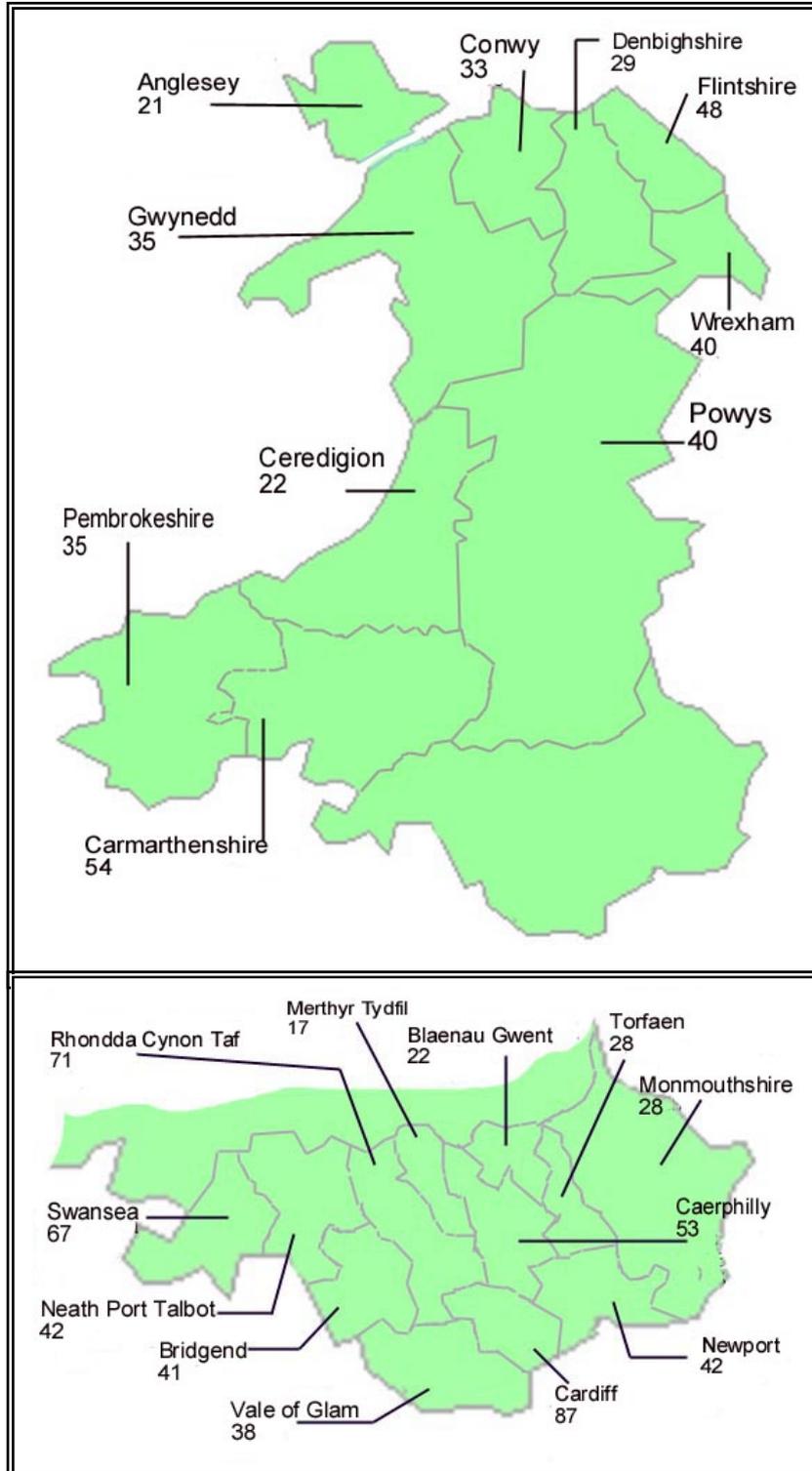
Using the prevalence data obtained from the Harvey et al. (1998) study it is possible to estimate the number of people likely to be suffering from young onset dementia in Wales. However, such estimates cannot take into account any local variations in disease incidence.

Based on an estimated prevalence rate of 67.2 per 100,000 in the 30-64 age group (Harvey et al. 1998) and using data from the 2001 Census we estimate that there are currently approximately 893 people suffering from young onset dementia in Wales. Table 1 details the estimated breakdown by local authority/ local health board area across Wales. This data is presented purely to give an indicative picture of the likely number of people with young onset dementia in Wales.

Table 1:
Estimated Number of People with Young Onset Dementia in each Local Authority / Local Health Board Area based on the 2001 Census Data

Local Authority/ LHB Area	Population aged 30-64	Estimated number of people with Young Onset Dementia
Blaenau Gwent	32170	22
Bridgend	60749	41
Caerphilly	78453	53
Cardiff	129029	87
Carmarthenshire	80202	54
Ceredigion	33286	22
Conwy	49342	33
Denbighshire	42421	29
Flintshire	71746	48
Gwynedd	51857	35
Isle of Anglesey	31272	21
Merthyr Tydfil	25849	17
Monmouthshire	41455	28
Neath Port Talbot	62782	42
Newport	62402	42
Pembrokeshire	52183	35
Powys	59909	40
Rhondda Cynon Taff	105258	71
Swansea	100124	67
Vale of Glam.	55847	38
Torfaen	42013	28
Wrexham	60203	40
WALES	1328552	893

Maps of Estimated Number of People with Young Onset Dementia in each Local Authority / Local Health Board Area based on the 2001 Census Data



5. Causes of Dementia in Younger People

5.1 Conditions

For the older population the most common cause of dementia is Alzheimer's Disease, accounting for approximately 60% of all dementias in this age group. While Alzheimer's Disease is also the most common cause of dementia in the under 65 age group it only accounts for approximately 30% of the cases. There are a greater proportion of rarer dementias present in this population. These have different symptoms and prognosis and may be more difficult to recognise and diagnose for professionals not familiar with them. Table 2. details the main causes of dementia in order of prevalence identified in the Harvey et al. (1998) study.

Table 2:
Causes of Young Onset Dementia and Prevalence Rates as Identified by Harvey et al. (1998)

Clinical Diagnosis	Percentage
Alzheimer's Disease	34%
Vascular Dementia	18%
Frontotemporal Dementia	12%
Alcohol Related Dementia	10%
Dementia with Lewy Bodies	7%
Other Dementias*	19%

*Other Dementias' included Huntington's Disease, Dementia in Multiple Sclerosis, Corticobasal Degeneration, Prion Dementia (CJD), Dementia due to Carbon Monoxide Poisoning, Dementia and Down's Syndrome, Dementia in Parkinson's Disease and Pre-senile dementia (no other cause specified).

It should be noted that the proportion of Frontotemporal dementia is high in younger people. In addition approximately 1 in 10 of the cases was an alcohol related dementia.

5.2. Genetic components

There is more likely to be a significant genetic component in young onset dementia than in dementia affecting older people. Harvey et al. (1998) found that 25% of those with a frontotemporal dementia reported a positive family history. Huntington's Disease has a recognised genetic mutation which can be tested for. The rare genetic form of Alzheimer's disease usually presents when the person is under 65. Watkins (2000) in a study of carers of younger people with dementia in South Wales found that sons were particularly worried about their risk of inheriting their father's condition.

6. Recommendations Relating to Specialist Services for Younger People with Dementia

6.1 The Royal College of Psychiatrists (2000) recommends

- • An identified individual in each commissioning authority with special responsibility for younger people with dementia
- • An identified Consultant in Old Age Psychiatry with special responsibility for younger people with dementia in each 'purchaser/provider consortium' working in close liaison with other key professionals
- • A dedicated specialist multidisciplinary team for populations of 500,000 and above
- • A specialist Community Psychiatric Nurse for smaller population groups
- • A key social worker in each locality

6.2 The Audit Commission in Wales in the report 'Losing Time' (2002) stated that 'there is an urgent need to explore cost-effective ways of delivering more individualised services to younger people with dementia' and recommended that Health Commissioners should 'consider how best to provide separate and age specific environments for people who require in-patient psychiatric care, particularly younger people with dementia.'

6.3 The Alzheimer's Society has published a Declaration of Rights for Younger People with Dementia and their Carers (1991). This calls for:

- • Fully informed medical assessment
- • Recognition of the need for specialist services
- • Support following diagnosis to include
 - ○ Specialist day care services
 - ○ Appropriate residential care
 - ○ Implementation of care management
- • Access to welfare benefits
- • Retrospective reinstatement of rights and benefits
- • Appropriate training and support

7. Services For Younger People with Dementia in Wales

7.1 Memory clinics

It is well recognized that the diagnosis of dementia in a younger person requires specialist expertise. Problems with and delays in diagnosis can create additional stress for younger people with dementia and their carers. Across Wales there are a variety of different routes that younger people may have to take in order to receive a diagnosis e.g. mental health services for older people, neurology services, adult mental health services. One route would be via the memory clinics/services that exist in some areas. The survey identified ten such services of which three were specifically for the 65+ population. Most services, including those with an age cut-off had seen some younger people with dementia. However there was a wide range in the number of people seen from 1 in the last year to 30. This may be a function of the type of service that is offered e.g. the frequency of clinics and access to diagnostic imaging. A separate report on these services is due to be published by the Dementia Services Development Centre Wales. However, it is clear from the survey that only a small proportion of younger people with dementia are accessing the Memory clinics that are available.

7.2 Genetic Counselling

The survey identified no genetic counselling services specifically for younger people with dementia. However, access to genetic testing and counselling is available in population centres e.g. at the University Hospital of Wales in Cardiff. There is also a nurse specialist for Huntington's Disease based at this hospital.

7.3 Day Care

7.3.1 Ty Agored Day Centre, Llysmadoc, Plasmadoc, Acrefare, Wrexham

This day centre is run and funded by social services exclusively for younger people with dementia. The centre is open for three days per week and offers six places on two days and three places on the third day in a small homely environment. They currently have 9 people on their register with some people attending more than one day a week. The staff ratio is 1:3. All staff are home care workers who have received additional training. The centre's support focuses mainly on activities of daily living to allow people to maintain their independence but also offers other activities and day trips. The younger people with dementia who attend are encouraged to help with the day to day activities for example, preparing the lunch.

7.3.2 The Tuesday Club, Glen Devon, 2-4 The Grove, Rhyl.

This club, which has been operational for one year, is run from a residential home base and offers 6 places on one day per week. Currently five younger people with dementia and their families are using the service, which is funded through the Carers' Strategy. The club is staffed by a manager and two carers. Much of the activity of the group takes place away from the base with trips to local museums and parks and regular swimming trips. The club has use of a computer and digital camera which members use to record their days out and other projects. The emphasis of the club is to provide social support in a friendly setting. Family members are also encouraged to become involved with the trips out and informal carer support is also provided.

7.4 Befriending

Services in Bridgend have used funding from the Carers' Grant to fund social care staff time to support younger people with dementia. The funding available is equivalent to 1 member of staff and the scheme has been running for one year. The befrienders provide social support and accompany younger people with dementia to recreational and social activities.

7.5 Residential and Nursing Home Places for Younger People with Dementia

7.5.1 Designated places

Responses from the questionnaire (which gave a sample of approximately 25% of care homes in Wales) indicated that a total of 21 beds (0.3% of the total) were available *specifically* for younger people with dementia distributed across 8 homes. **However**, 42 beds (0.6% of the total) are *currently* in use by younger people with dementia across 22 homes. Over the past year, a total of 61 clients who were younger people with dementia had been cared for in 29 homes.

Working from the estimate of 893 younger people with dementia in Wales, which constitutes 2.19% of the total population of people with dementia, younger people with dementia appear to be under-represented in residential and nursing homes in Wales. They constituted just 1.4% of the reported 3032 people with dementia in the homes responding to our survey.

In total, just seventy homes (30%) stated that they could accept younger people with dementia.

"We do take residents under 65, but at present only have 2 residents just over 60. I feel it wouldn't be appropriate to have young people with dementia with our very old people, as interests and activities are quite different."

"We have younger people with dementia in our day-centre, but because of registration, they cannot become residents."

7.5.2 Additional residential care places

We have recently identified a further two homes which provide care for younger people. Cedars in Crickhowell is an independent sector provision composed of three units which cater for people aged 18- 65 requiring nursing and respite care. The main unit has 29 beds and is intended for people with primarily physical health problems, The second unit, Cherrytree Lodge, has 12 beds and is intended for people with mental health needs. They also have a one bed-roomed flat for use by someone who is a danger to themselves or others. There is always at least one bed free for emergency respite care, and other places can also be used for respite care. The main source of referrals are Social Workers but referrals also come from special hospitals. There is no defined catchment area. Cedars operates a daily GP clinic and also has access to dietetics, speech and language therapy and a consultant psychiatrist. They also provide advocacy and counselling services for both residents and carers. They have one Welsh speaking member of staff.

The recently opened Arbennig Unit, Old Colwyn is an independent sector provision of an 8 bed residential unit based within a larger nursing home. The unit caters exclusively for people suffering from alcohol related brain damage who are under 65. It is anticipated that residents will stay for up to two years. There are plans to develop the unit so that it has a 6-bed admissions unit, 6 bedsits and 5 supported living flats. It is intended that people will progress through the unit and eventually live in the community supported by community outreach workers. It is planned that this should be ready in the next nine months. There may be the possibility of providing continuing care in the future.

The unit does not have a defined catchment area and the demand for the service is growing with people visiting from all over England and Wales. The unit is staffed by a manager with a nursing background and six staff. They also have access to psychiatry and physiotherapy and often have social work students. Although not able to offer formal carer support they find that due to the length of stay the carers and staff become very close. Services offered to

clients include advocacy and legal and financial advice. They also arrange day trips and support people doing voluntary work in the community.

7.6.Hospital Services

7.6.1 Tonna Hospital Younger Care Suite 4, Tonna Hospital, Tonna, Neath, West Glamorgan

This NHS funded unit offers respite care for four younger people on a continuing care ward. The team includes people up to the age of 72 in their criteria. Referrals come initially from the consultant to the Community Psychiatric Nurses who then refer to Tonna Hospital. The catchment area is limited to Neath and Port Talbot owing to a very high demand.

In the past the unit also provided day care for a two year period but this proved problematic due to the mixture of older and younger patients. Day care and assessment continues to be provided on another acute ward and four 'younger' people attend but there are similar difficulties in mixing older and younger people. Carer support and counselling is provided by this unit. Continuing care can be provided if required but again this necessitates a mixture of ages. The staff at Tonna report that there is a greater need than they can meet and have identified a need for more community based support.

7.6.2 Possible future development.

St. David's Hospital, Cardiff. This is a neighbourhood hospital providing intermediate care for patients suffering from dementia. Staff have identified six beds from within existing resources to be used for respite care for younger people with dementia but these have not been put into operation yet due to problems with medical cover.

7.7 Voluntary Sector

The Alzheimer's Society branch of Cardiff and Vale have a post of Development Officer for Services for Younger People with Dementia which is funded for three years by the National Lottery. The post aims to establish what provision is currently available for younger people with dementia and their carers and identify what services need to be developed. During this time the development officer will also provide information to all workers including

those in primary care and identify training needs for professionals. The development officer also works directly with younger people with dementia and their families offering assistance, advice, counselling and advocacy and is involved in the development of a comprehensive database.

7.8 Support Groups for Younger People with Dementia and their Carers

7.8.1 A dedicated support group for younger people with dementia and their carers has recently been started by the Development Officer for Services for Younger People with Dementia and the local Alzheimer's Society branch in Cardiff. This group is aimed at people living in Cardiff and the Vale of Glamorgan but has attracted interest from people living farther afield.

7.8.2 A support group for younger people with dementia in the Swansea area is provided every other Thursday at the Lodge at Garngoch Hospital. The group is facilitated by two community psychiatric nurses and an occupational therapist. Group members are already known to local services. The group is currently for ladies but they intend starting a group for gentlemen very shortly. Group members engage in activities they enjoy such as cooking and reminiscence. At the same time a parallel support group is provided for their carers. This often includes invited speakers to help with the distinct problems that younger carers may experience e.g. financial concerns.

7.8.3 We have also identified that carer support has been provided in the past by the South East Wales Dementia Careline, and the Vale of Glamorgan Crossroads but that neither service is currently providing this support. A support group for carers of younger people with dementia has also been provided at Tonna Hospital in the past.

7.9. Telephone Helplines

The South East Wales Dementia Careline is a telephone help-line that offers advice and support to carers and people with dementia. The Alzheimer's Society also offer telephone support through a number of their branches e.g. Cardiff, Swansea, Rhondda Cynon Taff.

7.10 Advocacy

To date we have identified ten advocacy services offering a service for people with dementia. Four of these services have an age criteria of 60 or 65 and above and report no contact with younger people with dementia. Those with a lower age criteria or no age criteria report seeing between 0 and 5 younger people with dementia in the last year. We identified only one dedicated service for those under 65 which did report contact with younger people with dementia. A detailed report on advocacy services for people with dementia is due to be published by the Dementia Services Development Centre- Wales.

7.11 Training

There were very few examples of specific training being available for those working with younger people with dementia. Some courses e.g. the SOLACE course provided by Cardiff and Vale NHS Trust include material on the needs of younger people with dementia and their carers. Practitioners have attended the annual U.K. wide conferences on Younger People with Dementia organized by the Alzheimer's Society.

7.12 Database Developments

Bridgend Database This database is held by the consultant psychiatrists working with younger people in the Bridgend area and is a clinical health database including details on nearly 100 people.

7.13 Possible Future Developments

Cardiff and Vale NHS Trust are in the process of developing a three-year pilot project to provide an assessment team to work in conjunction with the existing multi-agency mental health teams for older people. The plans also include the provision of some flexible day care.

Services in Pontypridd and Rhondda are currently reviewing their services for older people with mental health problems and developing a strategy which includes younger people with dementia.

Services in Bridgend are investigating the possibility of starting a day club.

8. Use of Services for Older People

From the results of our survey received to date it would appear that some younger people with dementia are accessing services designed for older people. For example of the 15 day hospital services that responded to the survey 8 reported that the service had been used in the last year by a younger person with dementia. Similarly, of the 20 hospital wards that responded 13 considered the ward or part of it appropriate for use by younger people with dementia. Only 3 wards responded suggesting that the ward was not used by younger people. The same would appear to be the case with community services where community teams for older people report seeing some younger people with dementia. However, only half of the domiciliary care providers who responded considered that their service could be accessed by a younger person with dementia.

9. Conclusions

The survey highlighted a dearth of provision for younger people with dementia. The relatively small numbers affected makes the provision of services outside centres of population difficult, and there is a great need for creative ways of providing the care that is required by some of those affected. Younger people with dementia tend not to be seen as the remit of any particular planning group or provider; they may be tagged on to older people's services, but are also seen in neurology and adult mental health.

The provision in the residential sector is clearly inadequate, in terms of numbers and the mix with provision for much older people. However, there are also examples of innovative services such as that catering for people with alcohol related problems that are attracting interest from throughout the U.K.

There is a clear need for an estimate of the need for such a service from within Wales. Ideally, younger people with dementia who require some form of residential or nursing care should be cared for in small units that are within travelling distance for their family and friends.

The survey also identified only two examples of dedicated day-care for younger people with dementia. Difficulties in providing a service for a relatively dispersed population will mean that creative alternatives to the traditional models of group day-care provision need to be identified. The befriending service in Bridgend was the only service of this type identified specifically aimed at younger people with dementia in Wales. There are a number of models of support being provided elsewhere in the U.K. that could provide a basis for the development of local service provision. For example the Clive Project in Oxford matches a younger person with dementia with a trained volunteer who provides one to one support to allow the person to continue with their chosen activities for as long as possible. This type of service has been available in North West Wales (2001-2003), through the Memory Support Service, operated by the Alzheimer's Society. This was one of six pilot projects, throughout the UK, funded for two years by the Mental Health Foundation. Although not targeted specifically at younger people with dementia, it has the potential to be highly flexible and individualised and age-appropriate. In the first year of the project, 3.4% of referrals were aged under 65. The future funding of this project is, however, uncertain.

We found no examples of consultant psychiatrists with special responsibility for younger people with dementia. There is a post in Cardiff where the previous post-holder had responsibility for services in addition to providing a service to a large sector. This post is currently vacant. We also found examples of consultants who have taken an interest in developing services e.g. the Bridgend consultants. Similarly, there are currently no dedicated teams or CPNs for younger people with dementia in Wales. The support currently available to younger people and their families is often provided by those who work with older people with dementia. Keady and Nolan (1999) describe the distress and anger that family caregivers experienced at having

to accept a service intended for older people. There is clearly also a need for the development of ways to provide emotional support to both younger people with dementia and their carers.

We also found only one example of dedicated in-patient hospital beds in the respite beds provided at Tonna hospital. However, difficulties in patient mix have been identified by this service suggesting that there may be a need for a different design of provision.

The example of a database as operated by the Bridgend service would seem to be an essential first step to assist in the identification of younger people with dementia and their health and social care needs. This could then contribute to the demographic profile and be used by commissioners of services. We would recommend that other areas investigate the merits of establishing such a database.

Throughout the production of this report we have encountered a wide variety of people in all sectors who recognise the need to develop services for younger people with dementia and are eager to investigate and embrace new models of service provision.

We would recommend the development of a network to support those working in this area and to assist sharing of expertise and training resources. This would also facilitate the evaluation of new service models and their replication or modification to enable development in other areas across Wales.

10. References

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11. Project Team

The following have made significant inputs to the service mapping project:

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Many thanks to all those in services in Wales who have responded to our questions patiently and courteously.

Identification of New Services

This report has attempted to identify all specialist services for younger people with dementia currently available. If you are aware of a service that has not been included or are in the process of developing a service the Dementia Services Development Centre- Wales would be keen to hear from you. Please contact

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