Cynulliad Cenedlaethol Cymru
Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

National Assembly for Wales
Health, Social Care and Sport Committee

Vaughan Gething AM
Cabinet Secretary for Health, Well-being and Sport

31 March 2017

Dear Cabinet Secretary,

Welsh Government's draft Dementia Strategic Action Plan

I am writing to set out the Health, Social Care and Sport Committee's response to the Welsh Government's current consultation on its draft national dementia Strategy. You will be aware that the Committee identified dementia as the first of its priority areas on which it would undertake scrutiny during this first year of the current Assembly.

We have taken evidence from key stakeholders, including people living with dementia, to gauge their views on the detail of the draft Strategy and whether it will deliver the changes required in dementia care.

The Committee clearly welcomes the launch of a five year Strategy. Having a long term Strategy should provide an important opportunity to make progress on a wide range of aspects of dementia care and a means of measuring over time whether that progress has been made. It should also be a means of delivering on the rights of people living with dementia.

We welcome the fact that the Strategy recognises that dementia is 'one of the most significant health and social care issues we face'. However we have concerns that, as currently drafted, the Strategy will not deliver the significant step-change that is needed for the estimated 40,000-50,000 people living with dementia in Wales and their carers.

We agree with the evidence we have heard which says that performance measures in the Strategy need to link in with key actions in the Strategy and need to be SMART.

They also need to better reflect the experiences and outcomes and quality of life for people with dementia.

There are some key concerns we have which are set out in this letter, along with our recommendations for change. Our recommendations are set out against the principles in the Glasgow Declaration, which the Welsh Government signed in 2015. Signatories to it have committed fully to promoting the rights, dignity and autonomy of people living with dementia. A summary of key points from the evidence we received is also set out in an Annex to this letter and provides a more detailed view on the wide range of provisions in the Strategy. The Annex includes very important issues and we urge you to give them full and due consideration.

The right to a timely diagnosis

The Committee has heard that Wales has the lowest dementia diagnosis rate of the four countries of the UK, at 51%. We note the Royal College of Psychiatrists view that ‘by 2021, each Local Health Board should attain a diagnosis rate of at least 75%’. They are also of the view that as an interim measure, by 2019 ‘Wales should learn from good practice to match the diagnosis rate in Northern Ireland (currently 64%)’.

The Committee is of the view that the percentage point difference between Wales and Northern Ireland is unacceptable. We are therefore very concerned about the proposed target of increasing diagnosis rates by only 3 percentage points annually in Wales. We heard evidence which suggested that a comparable diagnosis rate would not be acceptable for any other significant illnesses such as cancer.

We understand the rationale behind the evidence we received that the target is an appropriate one on the basis that it is realistic and achievable. We also heard that some GPs are reluctant to encourage diagnosis without feeling confident that services are available. However it is essential that people get the services they need based on a timely diagnosis and therefore a more ambitious target is needed.

Recommendation 1: A more ambitious target is needed for diagnosis rates in order that by the end of this five year Strategy, Wales has a diagnosis rate of at least 75%.

The right to access quality post-diagnostic support

We welcome the proposals that newly-diagnosed people will have access to a Dementia Support Worker (DSW) and we heard evidence of the importance of this role to people with dementia and their carers. However we heard that the number of DSW's proposed by the Welsh Government was widely believed to be insufficient. We note the performance measure of 'a minimum of 1 dementia support worker per 2 GP clusters in place across Wales' set out in the 'Together for Mental Health Delivery Plan 2016-19'. Witnesses suggested that this would result in 32 DSWs and that the workers would be overwhelmed by demand for their services. Alzheimer's Society Cymru/Wales told us that five or ten times the proposed number is needed. In addition we were told that DSWs are needed to cover the whole dementia pathway, not just the immediate post diagnosis period.

Support for carers

We are convinced that the draft Strategy needs to be clearer about the support that will be provided to carers. We heard that an estimated 37,000, people in Wales care for a person with dementia. Although challenging, given the wide range of support needed, there is a need for an additional performance measure relating to carers. We were told that the proposal in the draft Strategy to measure "numbers / % of carers offered an assessment and for those with 'eligible needs' to be offered a support plan" is too narrow in its focus and that it does not monitor whether actions included in the support plans were delivered. We agree that the Strategy should also include a way to measure improved well-being and outcomes, rather than measuring outputs alone.

Multi-disciplinary support

We heard that the Strategy does not recognise sufficiently the importance of multi-disciplinary support post-diagnosis. For example it was suggested that a new ‘key action’ be included in the Strategy which emphasises the role of LHBs, local authorities, housing providers, primary care clusters and third sector providers and which reflects a multi-disciplinary approach, including the role of Allied Health Professionals.

Recommendation 2: The Welsh Government should review the current performance measure of ‘a minimum of 1 dementia support worker per 2 GP clusters in place across Wales’, and set out a significantly increased baseline within the Dementia Strategy.

Recommendation 3: The Welsh Government should include an additional performance measure for support to carers so that the Strategy both reflects the wider range of support needed by carers and also references their well-being.

Recommendation 4: The Strategy should have a much clearer focus on the need for multi-disciplinary post-diagnosis support and include measures for monitoring this across a range of professions and sectors.

The right to person centred, co-ordinated quality care throughout the illness

We heard of the wide range of challenges faced by people living with dementia and also the specific difficulties experienced at specific stages. For example the challenges for people experiencing young onset dementia and their carers. We also heard about the need to significantly improve the care for those with advanced dementia, ensuring this is done in a way which respects the rights of that person as an individual.

Staff training and awareness

It is our view that the experience of people living with dementia and their carers could be significantly improved if the wide range of people who have an influence on the lives of people living with dementia had much more awareness of the illness. We welcome the target for 75% of NHS employed staff who come into contact with the public to be trained in the appropriate level of dementia care. We recommend that this training should include awareness of the role of carers and how to involve them in the care process.

We support calls for improved and more consistent awareness levels amongst GPs, often the first point of contact for people living with dementia. We recognise the key role of the social care workforce in delivering high quality dementia care. Therefore we also agree with the evidence that we have received about the importance of all staff across health and social care settings having the right training and level of awareness. This also includes staff such as catering staff, porters, and cleaners. Catering staff in particular need an awareness of how their role can impact on in-patients with dementia.

We have also heard evidence that the provision of psychological / behavioural training to staff to improve management of behaviours that staff find ‘challenging’ is patchy, very limited and not systematic. It is crucial that staff are supported to develop the skills to respond to the changed behaviour of people with dementia, which may be the result of confusion and distress. This is particularly the case in in-patient settings and nursing homes.

Palliative and end of life care

Witnesses welcomed the approach in the draft strategy to palliative and end of life care but were concerned that a clearer distinction needs to be made between them. We were told that the strategy should include separate themes for palliative care and end of life as key stages within the pathway. The draft strategy acknowledges a person’s right to decide where to end their lives but witnesses suggested that care home staff are often too ready to call an ambulance when a person’s condition deteriorates, meaning that their last days are often spent in hospital, contrary to their wishes. Better end of life planning could help prevent this being the default option and allow more people to die in their preferred environment.

Recommendation 5: The Strategy should include measures to ensure GPs have the appropriate levels of awareness of dementia.

Recommendation 6: All staff working in primary care, secondary care and social care settings who come into regular contact with people living with dementia, including non-medical and care staff, should have awareness raising training. The training should also include, as relevant, the NICE guidance on supporting people with dementia and their carers in health and social care.

Recommendation 7: Dementia training for health and social care staff should include awareness raising about the role of carers and how to involve them appropriately in the care process.

Recommendation 8: There should be evidenced based training developed and delivered on an all-Wales basis to develop the skills of relevant staff to respond appropriately to the changed behaviour of people with dementia.

Recommendation 9: The draft strategy should be strengthened in respect of palliative and end of life care. It should include clearer provisions to ensure that people with dementia are able to make timely advance decisions and plan for end of life. It should also require service providers to ensure that decisions around end of life are in the hands of people with dementia and that their wishes are respected wherever possible.

The right to equitable access to services

There are particular groups of people who will have distinct and specific requirements for their dementia care. This is affected, for example, by where people live, their language preference, and whether they have a protected characteristic.

We have heard about a wide range of circumstances where people need care and support delivered in specific ways, for example people whose first language is Welsh, deaf people, BME communities and the Gypsy, Roma and Traveller community. The Alzheimer's Society Cymru/Wales told us 'families are reluctant to use services that do not meet cultural or religious needs and try to carry on alone'. We also heard concerns about the challenges in delivering support in rural areas and a suggestion that services are designed for urban areas.

We are aware that concerns have already been raised with you requesting urgent consideration to holding further, additional dialogue about the Strategy with specific groups including the Gypsy, Roma and Traveller communities.
Whilst we welcome that the Strategy includes proposals to improve access to a diagnosis and care in the Welsh language, there remain a wide range of unacceptable barriers preventing appropriate dementia care being provided to all those who need it. The proposed action in the Strategy needs to be clearer about the Welsh Government's expectations on local health boards and local authorities.

Recommendation 10: The Strategy itself should be more specific and list the detailed actions that Welsh Government expect local health boards and local authorities to deliver with regards to the needs of the wide range of people who have additional, distinct and specific requirements for their dementia care. These actions should be developed in conjunction with relevant communities and groups.

The right to be respected as an individual in their community

We have seen first-hand how crucial it is to listen to the views of people living with dementia and their carers and to shape service provision according to their direct experiences. This will be key to the success of this Strategy and the work that it needs to deliver on over the next five years.

Recommendation 11: The Welsh Government should ensure that people living with dementia, including those with younger onset dementia, are actively and regularly involved in the Delivery Assurance Group overseeing the Strategy.

You will be aware that this Committee is undertaking an Inquiry into the use of anti-psychotic medication in care homes. We will look at whether there are specific issues affecting people living with dementia during that inquiry.

I look forward to receiving your response to this letter in due course.

Yours sincerely,

David R. Lloyd

Dr Dai Lloyd AM
Chair, Health, Social Care and Sport Committee

Annex A: summary of key issues

The Committee undertook a short inquiry on the Welsh Government's Draft Dementia Strategy. It took evidence from the following witnesses:

- Alzheimer's Society Cymru/Wales
- Age Cymru and Carers' Alliance Wales
- Royal College of Psychiatrists and Royal College of GPs
- Dr Les Rudd (Mental Service Improvement Lead, Public Health Wales)
- NHS Confederation
- Association of Directors of Social Services (ADSS) Cymru/ Welsh Local Government Association (WLGA)
- People living with dementia: Madeline Phillips; Michelle Fowler; Beti George; Nigel Hullah; Emily Jones and Karen Kitch.

Written evidence was provided by the above witnesses; by the Royal College of Nursing; the Care Council for Wales; the British Psychological Society; and a joint submission by the Chartered Society of Physiotherapy, Royal College of Speech and Language Therapists and College of Occupational Therapists.

01. Involvement of people with dementia and their carers in service planning and provision

There is universal agreement about the importance of involving people with dementia and their carers in service planning and delivery. Witnesses were positive about the extent to which people with dementia have been involved in the development of the draft Strategy and were concerned that such involvement should continue into the implementation phase.

Age Concern Cymru felt that the Strategy needs to be stronger on user involvement in service planning and delivery and that a performance measure on ensuring the mechanisms are in place for engaging with users and carers would help to underpin this.

02. Provision of dementia services for specific groups – equality of access

Witnesses emphasised the importance of **Welsh language services** for Welsh speakers and some welcomed the approach in the draft Strategy. There were some questions about the capacity of services to meet these needs. In written evidence the Royal College of Nursing (RCN) believed the need to improve Welsh language provision should have greater prominence in the draft Strategy.

There was concern about the relative lack of priority given in the draft Strategy to the development of services for people with dementia in **rural areas**. Witnesses highlighted issues around recruitment and retention of staff and the challenges of providing replacement care in rural areas where travelling distances are longer. A further issue identified was the lack of data on demand for services in rural areas.

The Committee heard that services should be strengthened for people with dementia from other groups, in particular **BME and LBGT communities**. We heard that services should be more responsive to distinctive language and cultural needs and ensure public health messages are reaching all communities, particularly given the higher rates of dementia in BME populations. Witnesses felt the draft Strategy needs to be stronger on meeting the needs of these groups. Other groups identified by witnesses as deserving greater recognition in the draft Strategy include prisoners, people with a learning disability, those with sensory impairment, people with early onset dementia and those who have experienced traumatic brain injury or the effects of alcohol misuse.

Lynne Neagle, AM, a member of this Committee, is also Chair of the Cross-party Group on dementia. In that capacity she forwarded a range of correspondence referring to issues relevant to Gypsy, Roma and Traveller Communities (GRT) and highlighting the growing evidence of dementia in these communities. The correspondence sets out the need to raise awareness of the increasing evidence and risk of dementia in Traveller communities. It also highlights factors which predispose to this and the additional difficulties experienced by Travellers with memory problems and the people that care for them. Concerns have been raised with the Cabinet Secretary along with a request for urgent consideration to holding further, additional dialogue about the Strategy with specific groups including the GRT community.

Michelle Fowler, who gave evidence on the panel of people living with dementia identified concerns about barriers facing **deaf people** either when the person diagnosed, or their carer, is deaf. Michelle told the Committee there is ‘absolutely no provision for deaf people with dementia in Wales’. She explained that ‘the diagnosis is very difficult because there are no specialists, and we would need to be diagnosed in a different way’. She also expressed concerns about the memory tests not being appropriate for deaf people. Michelle shared her own experience where, as the next of kin to her father when he was diagnosed with dementia, she was left out of the whole process because of being deaf and that other family members were contacted because they were hearing.

03. Communication support and support for swallowing, eating and drinking

In written evidence, the Royal College of Speech and Language Therapists (RCSLT), Chartered Society of Physiotherapy (CSP) and the College of Occupational Therapists (COT) expressed concern at the ‘scant references to communication’ within the Strategy. They point to the challenges of communication problems in all forms of dementia and say the Strategy should include access to communication support for people living with dementia and their families. They also express concern that there is no reference or actions within the Strategy to swallowing, eating and drinking difficulties.

04. Support for carers

In terms of carer support, witnesses highlighted issues around access to and availability of **respite/replacement care**, particularly in rural areas, which they believed the draft Strategy doesn’t get to grips with. There was support for a national approach to respite care.

There was criticism of the lack of performance measures relating to carers. The **high level performance measure** in the draft Strategy which proposes to measure "numbers / % of carers offered an assessment and for those with 'eligible needs' to be offered a support plan" was seen as having a narrow focus which doesn't reflect the carers' journey. It was felt that the performance measure could be reduced to a 'tick box' exercise which doesn't measure outcomes for carers. Witnesses pointed out that many carers receive support in other ways which would not be captured by the measure.

There was a view that **families/carers and their roles are not sufficiently well understood or included** by service providers and that this needs to be addressed in the draft Strategy. In addition, we heard that education and training are needed for families and carers to help them understand dementia, how to cope with the progression of the condition and how to support the person they care for, including situations where the dementia affects behaviour.

05. Diagnosis

There was some discussion about the merits of the proposed target in the draft Strategy of **increasing diagnosis rates by 3 percentage points per year**. Some witnesses believed the target is realistic and achievable, others believed it is not sufficiently ambitious, particularly given that Wales has the lowest diagnosis rate in the UK. It was pointed out that, with a 3 percentage point annual increase, Wales would still only achieve a 64% diagnosis rate by the end of the lifetime of the Strategy.

Some evidence highlighted an issue with the new **counting methodology** which does not include younger people with dementia (under the age of 65 years). Witnesses told the Committee that this makes it harder to keep track of people with early onset dementia, who have very specific and different needs, and there is a risk that their needs will not be taken into account.

The **28 day waiting time target for a first assessment and 12 weeks for a working/preliminary diagnosis** was welcomed but witnesses noted the long waiting times currently for memory clinics in some areas. This suggests additional resources will be needed to meet the target.

Others believed that diagnosis is only helpful if support services are in place for people with dementia and there was a suggestion that some GPs are reluctant to encourage diagnosis without feeling confident that services are available. It was suggested that a higher diagnosis rate target would therefore have resource implications along the whole patient pathway.

There was some discussion about which professionals are best placed to **make a diagnosis of dementia** with some witnesses emphasising the importance of specialist knowledge and skills, and others that GPs and a range of other health professionals should be involved. The importance of accuracy was emphasised; a diagnosis of dementia has profound implications for individuals and their families and the condition is incurable. Witnesses suggested that a discussion is needed about what is meant in the draft Strategy (p20) by diagnosis by a ‘competent clinician’.

06. Service configuration

There was universal support for greater **service integration** but an acknowledgement that this Strategy alone could not achieve it on a wide scale. Regional working and pooled budgets were advocated. Witnesses said there is little reference in the draft Strategy to the important contribution of **housing services** in allowing people with dementia to remain in their own homes. The Royal College of Speech and Language Therapists (RCSLT), Chartered Society of Physiotherapy (CSP) and the College of Occupational Therapists (COT) emphasised the key role that Allied Health Professionals have in dementia care. They say that the Strategy ‘misses a crucial opportunity to set out a new vision for how care could be delivered differently by enhancing a multi-disciplinary approach’. They also suggest a new ‘key action’ for LHBs, local authorities, housing providers, primary care clusters and third sector providers which reflects this multi-disciplinary approach, including the role of the Allied Health Professionals.

07. Care and support in community settings

The number of **Dementia Support Workers** (DSW) proposed by the Welsh Government was widely believed to be insufficient and witnesses suggested the proposed 32 DSWs would be overwhelmed by demand for their services. Alzheimer's Society Cymru/Wales suggested that five or ten times the proposed number is needed. In addition DSWs are needed to cover the whole dementia pathway, not just the immediate post-diagnosis period. The RCN called for clarity about the role and qualifications expected of DSWs and for recognition of the role of dementia specialist nurses.

Other evidence highlighted the involvement of other community based staff who play a key role in supporting people with dementia; such staff will need additional training. There was some criticism of the emphasis on Community Mental Health Teams as support providers with witnesses stating that dementia is not a mental illness.

08. Care in hospital settings

There is compelling evidence that a **hospital setting** is rarely the best environment for people with dementia. Nevertheless, many people with dementia are treated in hospital, (the Committee heard that 25-40% of people in hospital have dementia) often because they have co-morbidity. Furthermore, 84% of people admitted to medical and surgical wards are over 85 and a significant proportion of them have mental health problems and /or dementia, in addition to other health problems. It is therefore important that the hospital environment is dementia friendly both in terms of building design and staff training.

A further issue is **access of carers and families to hospitals**. Witnesses believed that a rethink is needed on managing people with dementia and the involvement of relatives on hospital wards. The Carers' Trust told the Committee it didn't believe the key actions in the draft Strategy will address this issue.

There was concern that the **health needs of people with dementia** in hospital are not being addressed in the round and that too often patients are moved between healthcare settings rather than receiving integrated services. Witnesses highlighted the lack of emphasis in the draft Strategy on physical health and co-morbidities. Others argued that dementia is not a mental health condition and that dementia patients should not be ‘pigeon holed’ into mental health services. It was suggested that more joint care wards are needed.

09. Care in residential settings

The draft Strategy refers to the ‘Direct Enhanced Service’ (p44) which aims to improve health care provided by GPs to care home residents. It includes a key action for “Health Boards to ensure implementation of care homes Direct Enhanced Service”. However, in oral evidence, the Royal College of GPs was not familiar with the details of the scheme and felt unable to comment on it. Nevertheless, it was acknowledged that better healthcare is needed for care home residents and that medical advice and support for care workers, and good care plans, can help to minimise hospital admissions. In addition, we heard that better communication is needed between hospitals, GPs and care settings to maintain consistency of care.

10. Anti-psychotic medication

There is concern about the inappropriate use of anti-psychotic medication and some witnesses were pleased the issue is reflected in the draft Strategy. It was acknowledged that there is work to do to address the problem. This includes raising staff awareness of the underlying reasons for agitated or distressed behaviour in each individual, which itself requires a person centred approach to care. Witnesses believed that not enough is being done to ensure regular medication reviews; the Strategy could be stronger on this. Other witnesses expressed doubts about whether the draft Strategy will address the problem, given the lack of prescribing data with which to assess the extent of, and reasons for, anti-psychotic prescribing.

There was also some scepticism about the **availability of alternatives**. We were told that more occupational therapy support for example, particularly for people living at home or in residential care, would help to reduce anti-psychotic prescribing.

11. Palliative and end of life care

There was praise for the key actions in the draft Strategy around training staff to help people and their families plan for end of life care. However, witnesses emphasised the importance of allowing people to die in their place of residence rather than in hospital and believed the draft Strategy could be strengthened in this respect. The Spice project in Swansea was cited as an example of good practice in this area. Witnesses believed there is a need for the draft Strategy to recognise the distinction between palliative care, which aims to mitigate the effects of symptoms and can extend to a number of years, and end of life care which may last for only a few weeks or months.

12. Staff training and development

Dementia training for health and social care professionals is seen as central to the provision of good care and a dementia friendly environment. There was praise for the target in the draft Strategy of training 75% of NHS staff but witnesses emphasised the importance of **training for all staff across health and social care**, particularly in primary care which is the first point of contact with health services for many people with dementia. The RCN believed the draft Strategy should set out specific requirements for people with dementia to receive care from staff trained at a level appropriate to their needs.

In addition, witnesses emphasised the need for staff training to include **awareness of the role of carers** and how to involve them in the care process. The Carer's Trust and the RCN referred to the *Triangle of Care* they have developed which sets out the relationships between the person with dementia, professional and carer and aims to promote "safety, support communication and sustain wellbeing". The *Good Work; A Dementia Learning and Development Framework for Wales*, developed by the Care Council for Wales and the Welsh Government, is regarded as a useful tool. It aims to meet the needs both of staff and people with dementia and their carers. Written evidence from the Care Council for Wales called for more consistent application of the framework across Wales.

A particular issue regarding people with dementia in hospital settings is the way healthcare staff respond to the **changed behaviour of people with dementia**, which may be the result of confusion and distress, but which requires specific skills to manage. Given the prevalence of dementia in acute settings, it was argued, this is an issue which should be prioritised. However there are capacity issues in terms of appropriate staff to provide such psychologically based training.

Although some witnesses praised the broad approach taken by the draft Strategy to training and awareness which they believed could be built on, others suggested that it does not go far enough in fostering the culture change that is required across all services to ensure that dementia is prioritised.

13. Resources

Witnesses agreed that the Strategy has resource implications, although there was a suggestion that closer scrutiny of the £1.4bn currently spent on dementia services might result in better use of the money. The Committee heard that some service improvements are not resource intensive, such as sharing best practice and culture change. Other areas, such as improving diagnosis rates, provision of dementia support workers and improvements to social care would require additional resources but may lead to long term savings. Whilst it is resource intensive, staff training is seen as an important investment. Witnesses stated that spending on community based services and third sector services often provides best value for money.

14. Targets and performance measures

There was some criticism of the proposed measures in the draft Strategy. Witnesses emphasised the importance of measuring the experiences and outcomes and quality of life for people with dementia. Measures need to be

SMART and the performance indicators need to link in with key actions in the Strategy.

15. Inclusion of people with dementia and carers on Delivery Assurance Group

Witnesses were positive about the involvement of people with dementia and their carers in the development of the Strategy and they were anxious to ensure that involvement continues into the implementation phase. The Committee heard that the Older Persons' Delivery Assurance Group, which will oversee delivery, needs to include representation from all sectors, including social care, housing and the third sector, as well as people with dementia and their carers. We were told that at present it appears to be too health orientated. The RCN called for more detail in the draft Strategy on the role and level of accountability of the DAG.

16. Evidence from people with dementia and carers of people with dementia

Members of the panel provided powerful evidence of their own experiences of dementia, underlining the need for service improvements and the importance of developing an effective dementia Strategy in Wales.

Diagnosis

There is a need to move away from a medical model of dementia diagnosis towards a more holistic approach which recognises the psychosocial aspects of the condition. Dementia does not need to be diagnosed by a medical practitioner, for example psychologists can play a role. It can take a long time to receive a diagnosis, during which time other aspects of life can become increasingly difficult.

There is a serious lack of provision for deaf people in Wales, including specialist diagnosis support. At present deaf people have to travel to England to receive specialist support. Existing assessment tools may not always be appropriate, for example memory tests may not take account of the lower levels of literacy/education of some deaf people.

The target for increasing the diagnosis rate in Wales by 3 percentage points per year, whilst welcome, is too low.

Post diagnosis support

A diagnosis of dementia is difficult to cope with and it is important not to feel alone – more support should be provided. Support from both peers and Dementia Support Workers is needed.

The problems are magnified for deaf people, for whom there is little recognition of communication needs and a lack of accessible information, for example in British Sign Language.

Fully accessible information should be provided which includes contact details of an individual who can give information and guidance on the range of issues facing people with dementia and their families and carers.

Carers

Provision of support and information on dementia for carers and family members is essential to help them understand the condition and its implications, and to know which services are available and how to contact them. The absence of such information and support is disempowering and can have a major impact on the wellbeing of carers.

The onus should be on service providers to reach out to people otherwise they may remain isolated and unsupported, particularly young carers. Support services should not be offered only in response to a crisis.

Peer support is very helpful for carers – it is important to have someone to talk to.

Hospital treatment

Hospital treatment can be traumatic and detrimental to the overall wellbeing of a person with dementia. Care is not person centred, staff are under pressure, and services are disjointed. Healthcare professionals need to have more faith in carers. A named person needs to be available to help, similar to Link Workers in

Scotland. There should be a dementia unit, easily contacted and open 24 hours a day, in every local health board area.

Anti-psychotic medication

A pharmacological approach to managing and treating dementia is wrong. Anti-psychotic medication should only be used as a last resort. Deaf people may be misunderstood and wrongly prescribed antipsychotic drugs as a result of the inability of services to communicate effectively with them.

Training

There is a need for better training on dementia for all staff working in dementia services and for others including, for example, hospital porters and catering staff and people working in shops and banks. Dementia friendly communities have a role to play here.

Staff working in dementia services need to be respected and properly remunerated, otherwise there will be a recruitment crisis.