

Growing old my way

A review of the Impact of the National Service Framework (NSF) for Older People in Wales

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Copies of all reports, when published, will be available on our website or by contacting us:

In writing:

**CSSIW National Office
Government Buildings
Rhydycar
Merthyr Tydfil
CF48 1UZ**

**Communications and Facilities Manager
Healthcare Inspectorate Wales
Bevan House
Caerphilly Business Park
Van Road
CAERPHILLY
CF83 3ED**

Or via

Phone: 0300 062 8800

Email: cssiw@wales.gsi.gov.uk

Website: www.cssiw.org.uk

Joint Inspectorate Website: www.inspectionwales.com

Phone: 029 20 928850

Email: hiw@wales.gsi.gov.uk

Website: www.hiw.org.uk

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Foreword

It gives us great pleasure to introduce this report that looks at whether the National Service Framework (NSF) for Older People in Wales¹ has achieved the changes and improvements to services for older people across Wales that were intended when it was introduced in 2006.

Due to improvements in medicines, technology and working and living conditions people are living longer. According to recent figures, people aged 50 or over in Wales account for 37% of the total population, while those aged 60 or over make up 24%². In comparison, in 1961 only 18% of people living in Wales were aged 60 or over, while those aged 80 or more accounted for just 2% of the total population, compared with a figure of 5% today³.

The NSF was introduced in recognition of the growing number of people living past the age of 50 and the need to ensure that they are provided with the health and social care that they require to support them to live a longer and fulfilled life. The NSF is a key strand of work to arise from the Strategy for Older People in Wales, published in 2003⁴. The Strategy emphasised the importance of engagement, participation and empowerment of older people and the importance of enabling older people to live their lives as actively and independently as possible in a suitable and safe environment of their choice.

A key concern highlighted very early on in the planning and scoping of this review was the increasing numbers of people who have dementia and the widespread view that

¹ The National Service Framework for Older People in Wales, published by the Welsh Government, March 2006.

² Mid-2007 population estimates for UK, England and Wales, Scotland and Northern Ireland. United Kingdom, Office for National Statistics website. August 2008.

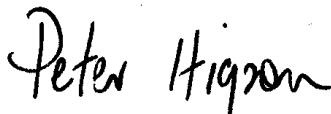
³ Mid-year population estimates 2007. Welsh Government, Statistical Directorate, StatsWales website. August 2008.

⁴ The Strategy for Older People in Wales 2003-2008 Published by the Welsh Government November 2003.

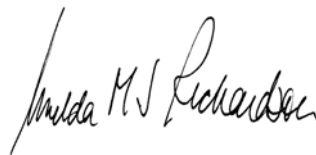
often dementia is not diagnosed early enough and appropriate treatment is often not given. Such were the concerns that we decided to look at the application of the standards set out in the NSF through the *'lens of someone with dementia.'*

We are extremely grateful to all those people over the age of 50, service users, carers and relatives who helped us to compile this report by openly sharing with us their thoughts, views and experiences. Some had very sad stories to tell about their experiences and frustrations in accessing services, others had nothing but praise for their local services. We hope that all those we spoke to will recognise their input and stories from the findings and recommendations we have made in this report. We have started our report with *'Dad's story'* a true account of a family's recent experiences. We hope it will encourage all who read it to stop, think and ask questions.

We hope that the information set out in this report will be of interest not only to those responsible for providing care to older people, but also to individuals and their families who are or could be in need of health and social care services in the future. Not one of us can escape the ageing process but we can and should be supported to age with dignity and in the way that we choose - *'our way.'*



Peter Higson
Chief Executive
Healthcare Inspectorate Wales



Imelda Richardson
Chief Inspector
Care and Social Services Inspectorate
Wales

Dad's story

Dad was in his early seventies when he first started to show signs of something not being right. He got emotional and upset over things that he would normally have just let go over his head. At first his GP put it down to depression, however his symptoms got worse – it wasn't so much his memory loss but his hallucinations and what my mother called the night horrors where he would wake up confused thinking he was back working *'down the mine.'*

After a while he was referred for a mental health assessment and for some reason a man who had worked hard all his life, brought up four children and held down responsible jobs was diagnosed as being bipolar. My sisters and I couldn't believe this and challenged it; he had never drunk to excess, never gone on wild splurges and we who had lived with him all our lives were totally taken aback. How could such an assessment be made? I watch the cine films of our childhood holidays, of Christmases and days out, there is no way on earth that my father was bipolar.

Over time the usual signs of dementia got more frequent. He would wake up not knowing where he was and forget what he had just done. He was referred to the local memory clinic and following a series of assessments was diagnosed

with Lewy Bodies dementia⁵. Dad was allocated a Community Psychiatric Nurse (CPN) and Mum was referred for counselling. The local Alzheimer's society provided wonderful support and Mum and Dad went on days out and attended the Alzheimer's Cafe. Also twice a week Paul came to take Dad out for the afternoon; he loved these breaks and became very fond of Paul. Things were ticking over just fine and with the support of the Alzheimer's society Dad had been supported to put arrangements in place for the future, including giving family members Power of Attorney.

In October 2009 Dad was asked if he would go into hospital for two weeks so that he could be properly assessed and his medication adjusted. We were upset when we left him on the day of his admission as the ward was clinical and not the friendly and therapeutic environment we expected. Even Dad's individually wrapped Werther's Originals were confiscated to the kitchen, apparently an infection risk. Patients sat around in one big room and during Dad's stay we never saw the newly refurbished patients' sitting room open. We only saw it being used for meetings.

During the first week of his stay Dad told us that he found it difficult to have a conversation with any of the patients and commented that he was fed up of watching many of them just walking up and down the corridor. Sadly, by the second week Dad had joined them.

⁵ Dementia with Lewy Bodies (DLB) is a form of dementia that shares characteristics with both Alzheimer's and Parkinson's diseases. It accounts for around ten per cent of all cases of dementia in older people and tends to be under-diagnosed.

We were devastated as he had walked into hospital two weeks earlier after having just returned from a holiday in France, he was relatively fit and well and to those who didn't know him he showed no signs of dementia.

As the weeks progressed he got worse, he developed a stoop and we noticed that he had started to dribble, he cried when we took him back to the ward after a walk in the grounds. Almost all lucid conversation had stopped and he started to exhibit behaviour that was just not him; he was incontinent and got aggressive when he found that he could not leave the ward. Due to him having toppled the wardrobe in his room and dismantled his bed on more than one occasion all possessions and furniture were removed from his room. It was devastating to see him in this environment.

From the start of his decline we as a family queried whether it could be his medication. The staff said we had to accept he was deteriorating, when my mother asked about having him home she was told that he needed nursing home care with at least two carers looking after him at any one time. We couldn't accept this - how could he have gone down- hill so fast?

We asked for a list of all his medication and found that he was on atypical antipsychotics and a cocktail of tranquilising medication including diazepam and triazepam. We then began to research the internet accessing the Royal College of Psychiatrists site and NICE guidelines. We were horrified to see the

possible side-effects of all his medication and specifically the dangers of using atypical antipsychotics on someone with Lewy Bodies.

My family asked for a meeting with his Consultant Psychiatrist, when we questioned the medication Dad was on she told us that we had no right to question her clinical judgement as she had trained for seven years and we had only looked at the internet.

We were incensed and requested a second opinion. The Consultant who provided the second opinion in January 2009 was wonderful and as a result all medication was stopped. Dad was home within two weeks but he had gone through hell for two months.

Mum wanted Dad to stay with his consultant as she felt he wouldn't cope well with a change. For two years things were looking good, Dad was on Aricept and it seemed to suit him. Mum and Dad pottered about together happily and during this time they went on more trips and short breaks with the Alzheimer's society.

Over time visits from the CPN got less and less and when my mother or younger sister rang her she groaned about her case load and said that Dad wasn't as ill as others. We asked my mother about Unified Assessments, a Care Plan and a Carer Assessment she said she had never seen any of these. We know a

very basic one was completed during his in-patient stay in 2008-09 but this wasn't holistic and certainly would have been no longer appropriate.

Then in October 2010 Dad began to develop a tremor in his right hand and unbeknown to my sisters and I his Aricept was stopped. The bad weather during November meant that my mother and father were unable to go out on their usual jaunts. Dad began to sleep during the day and was awake most of the night. The pressure on my mother was building. Numerous calls to Dad's CPN were made and messages left. Mum and Dad felt abandoned. When Mum did eventually get hold of her she said that due to funding there wasn't a lot she could do. Dad got worse, he became doubly incontinent and we brought his bed downstairs as he was unstable on his feet and had started to regularly drop to the floor as though dizzy.

Eventually it was arranged that carers would come in to help him to bed each night and sit with him for two nights a week. My sisters and I covered the remainder. During this time Dad still had long periods of being lucid and his dry sense of humour was still evident. Then my mother was told that the sitters and carer input was time limited due to funding. My mother was near breaking point and was finding it difficult to cope. I was in work one day and my sister called to say that they were admitting my father to hospital that day for two weeks respite.

I was shocked when I went to visit him, that night they had admitted him to the Psychiatric Intensive Care Unit (PICU). My wife and I couldn't understand why and the staff seemed equally confused. We never got to the reason why but hope that what we strongly believe was an erroneous diagnosis of bipolar during the early stages of his dementia wasn't the reason.

The staff on the PICU were wonderful to Dad; but he still shouldn't have been there. Their expertise isn't in the care of the elderly. Dad stopped eating and drinking and the nursing staff on PICU were concerned. It turned out that Dad had been on a series of atypical antipsychotics since October and his Consultant told us that she thought Dad had suffered a series of mini strokes. Dad was eventually transferred to an older people's' mental health ward in a neighbouring hospital.

My wife and I went to visit him and were shocked and upset to find him lying on a mattress on the floor of the quiet room. The staff were wonderful with him but by now he was finding it hard to keep his eyes open and there was little communication. We talked to the nursing staff and raised our concerns that his condition was due to medication rather than deterioration. They were patient and listened to us, they noted in his records our concerns about his medication and the fact that he had not been given a CT scan despite his Consultant feeling that he may have had mini strokes. Dad had a scan the next day, it showed no signs of stroke.

Despite the loving care provided by the nursing staff Dad continued to deteriorate, he was not eating or drinking. He was still under the care of the same consultant and she still continued to prescribe Olanzapine, although she had reduced the dosage slightly.

In desperation we requested that Dad's care be transferred to the consultant who had provided a second opinion in January 2009. Before agreement to the transfer of Dad's care he started to go into renal failure. By now he was sleeping most of the time and there was no sign of that dry sense of humour. Dad was put on a drip and we were told it was a matter of time. It was during this time that agreement was reached that his care be transferred and his new consultant stopped all his medication.

Dad hung on in there and within days he was off his drip, slowly he got stronger and he was back, not quite as he was before he went into hospital but wicked enough to tell my wife when we visited yesterday that he once had a pair of curtains like her dress. Dry enough to tell me when I asked what advice he had for me in relation to putting a steel girder in place, that the only advice he had was *'Best of Luck.'* The staff on the ward are amazed, I think they think it is a bit of a miracle and they are loving and cherishing him. He is currently so content that he keeps on telling us how wonderful his *'hotel'* is, there are no tears like we had when he was an in-patient before.

If Dad had died three weeks ago I would never have forgiven myself, I would have felt like I had let him down. I hope that he has many years left but if he hasn't at least I know that he is now getting the best care.

My Dad once had a strong voice that we kids would hear from the fields near our house when he called us in for dinner. His voice is not so strong anymore and that is why my sisters and I have to be it.

I wanted to tell Dad's story not to worry or concern other people who are in a similar situation but to empower them to ask questions and to not accept that clinicians always know best. Many parts of Dad's care have been good and both he and my mother have been given invaluable support by people like Paul and the Alzheimer's society. Dad's new Consultant wants us to ask questions, he listens and has told us that the family often know what's best for their loved one.

My message to all who read this is question and query the care and treatment provided to your loved ones. If you feel that you are not in a position to be your loved one's voice there are professional advocacy services available who will provide help, support and advice. I assure you enlightened clinicians want to listen.

Executive summary

In our review we looked at seven of the ten standards established in the National Service Framework for Older People in Wales using the pathway of an individual with dementia; to enable us to provide an answer to a key question - '***What impact is the NSF having on the quality of life of older people in Wales?***'

It can be said with certainty that the NSF has had an impact. Together with related strategies and the role of the Older People's Commissioner for Wales⁶, it has raised the profile of older people in Wales and highlighted the need for them to be treated as individuals and without discrimination. All those who participated in our review valued the focus that the NSF has brought to the need to think innovatively and '*outside of the box*' when providing care and support to older people.

However, the full implementation and consequent benefits of the NSF are still a long way off. Health and social care still have a lot to do in terms of refocusing their approach and agenda to one of prevention and empowerment.

The National Dementia Vision for Wales⁷, launched by the Welsh Government and the Alzheimer's Society in February 2011 recognises many of the issues highlighted in this report. It identifies four priority areas:

- improved service provision through better joint working across health, social care, the third sector and other agencies;
- improved early diagnosis and timely interventions;

⁶ The Older People's Commissioner for Wales came into being on 21 April 2008. Ruth Marks was appointed as the first Commissioner.

⁷ The National Dementia Vision for Wales was launched on 16 February 2011 by the Welsh Government and the Alzheimer's Society. It highlights the support and advice available to anyone diagnosed with dementia.

- improved access to better information and support for people with the illness and their carers, including a greater awareness of the need for advocacy; and
- improved training for those delivering care, including research.

The guidance necessary to address the issues raised in this report is therefore already in place. Now what is needed is a period of consolidation with a strong focus on implementation rather than writing more policies, strategies and NSFs.

A certain degree of bravery is needed by statutory health and social care agencies in being honest in their assessment of what they are good at and not so good at and then doing something about it. They need to look more to third sector agencies to help them drive this agenda where they can better provide what older people need.

There is an inherent tension between a preventative approach and an eligibility framework that targets the highest needs as priority. This must be tackled if service providers are to deliver early intervention to support the independence of people in need of support and although this report is based on dementia it is equally applicable to all chronic conditions that affect older people such as respiratory disease and diabetes.

Collaboration between health, local authorities and third sector organisations is needed to help to deliver the changes needed. This important agenda cannot be achieved by organisations working alone or in parallel. Future services must be able to respond to the holistic needs of older people living with dementia.

Health promotion, well-being and prevention

One of the key aims of the NSF is to keep us healthier in older age. The NSF therefore promotes more proactive and systematic health checks for older people and the provision of community-based activities that encourage a healthier lifestyle and emotional well-being.

The provision of coordinated and holistic health promotion and prevention services is of fundamental importance to the quality and dignity of us all as we grow older. They can help you to stay well and keep living life the way you want to for longer.

Our review has highlighted that across Wales a number of innovative and valuable services and support mechanisms have been put in place. We were told that schemes and services that worked well were:

- exercise and activity classes;
- lunch clubs;
- shop and drop internet services such as the Food Solutions Project in Flintshire; and
- television adverts such as the FAST advert for stroke.

However, there is variation in provision and in many areas there are still gaps. In particular more needs to be done to:

- coordinate and advertise activities locally;
- support those older people with substance misuse issues; and
- address the sexual health agenda for older people.

Knowing what services are available and what you are entitled to can make practical and positive differences to your day-to-day life. At a local level, we found it difficult to find out what services are available and when, and were told by stakeholders that this was often a problem for them. For example, we sampled a number of local authority and health board websites and found that it was nearly impossible to find information on older people services and groups on many of them. Rhondda Cynon Taf County Council's website was one of the exceptions with the front page clearly signposting information for older people. A number of local authorities in collaboration with health boards issue a newsletter which is delivered to every house in their area. We were told

that such newsletters are key to providing information to those who live alone and are isolated.

Greater investment is needed at a local level in health promotion, prevention and community services if we are to help and support people to live healthy and longer lives. This is the biggest dilemma for statutory agencies as the impact and benefits of such investment for them will not be immediate but longer term. They need to work more closely with the third sector to see how together they can put a cohesive approach to promotion and prevention in place. In recognition of the fact that Wales requires a step change in its approach to developing both policy and service delivery models for primary and community care the Welsh Government published '*Setting the Direction*⁸.' This sets out a framework to assist statutory agencies to develop and deliver improved primary care that is proactive, coordinated and focused on prevention.

Maintaining independence at home for as long as possible

From our consultations with people with dementia and their carers and relatives it is clear that those with dementia do not always receive good person centred care. Quite often care is fragmented and reactive rather than proactive and responsive. There was however glimmers of progress and improvement, with most of the health and social care professionals recognising the need to change practice and work together. As part of the Welsh Government's Invest to Save Initiative, a £9 million support package was granted to the '*Gwent Frailty Programme*' in September 2010. This programme is looking to create an integrated model of care that is community based. The Gwent Frailty Programme is just one example of innovative approaches being taken forward across Wales.

Health and social care organisations need to listen to what users of services are saying, which is that: '*People with dementia are individuals, with individual needs, likes and*

⁸ Setting the Direction, Primary & Community Services Strategic Delivery Programme, Welsh Government, 2010.

*dislikes. Their uniqueness must be understood and respected and this was not always their experience.*⁹’

Providing care to people with dementia often in the later stages of their lives can be both difficult and demanding. Comprehensive care planning that includes all the available information about the service user and their preference for care is important. In a recent King’s Fund report¹⁰ 75% of those surveyed said they wanted to choose where they were treated, yet less than half said they had been offered a choice. This accords with the Age Alliance work undertaken as part of this review; 75% of participants expressed frustration at the lack of choice and dependency on traditional services.

Recent statutory guidance aimed at ensuring greater consistency in charges for non residential social services will hopefully result in a fairer and more affordable approach to the provision of services. It should also help to rebalance services towards prevention and early intervention and in so doing help improve people’s choices.

It is clear that the third sector have a lot of experiences and skills to offer and all health and social care organisations need to work together and identify where they can best influence and improve services. Also, primary care practitioners and in particular GPs need to be better engaged in a team approach to care and support as their role is critically important in ensuring access to appropriate and timely assessment.

Awareness and training of health and social care staff and the public in relation to the signs and symptoms of the early stages of dementia is key to ensuring early and timely intervention. If we are to help those with dementia live happy and fulfilled lives for as long as possible we need to look to interventions that are therapeutic in nature and only

⁹ A preliminary analysis of Dementia in Wales. Published by the Care and Social Services Inspectorate for Wales in July 2010.

¹⁰ Patient Choice, How Patients Choose and How Providers Respond, King's Fund, June 2010.

turn to medication as an alternative either where it has a clear therapeutic benefit or is absolutely necessary.

Maintaining independence while in hospital and ensuring that people are not discriminated against because of age

People train to become doctors and nurses because they want to care for people. A key message that has come out of this review is that sometimes *'caring is translated into doing to and for.'* It is important that healthcare staff remember that they have a key role in supporting individuals to maintain their dignity and independence as long as possible. A key aspect of this is involving them in every aspect of their care and empowering them to make informed choices and decisions.

Long hospital stays can have an impact on independence and confidence whatever your age or diagnosis but for those with dementia the potential impact is greater and so any hospital stay should be avoided unless there is a very real clinical need. When admission is necessary health and social care staff should work with the individual, carers and relatives to ensure a timely and well planned discharge.

The provision of a therapeutic environment and stimulating activities should form part of the routine on older people's wards and care and support should be holistic.

The findings set out in this report have been shared with the Older People's Commissioner for Wales as part of the evidence gathering for her report *on 'Dignified Care?'*¹¹ We are working closely with the Commissioner and the Board of Community Health Councils¹² to ensure that the experiences of those with dementia are improved.

Next steps

We started to pull together a long list of recommendations to be issued with this report and realised that we were just repeating what has already been said in various strategies and reports, not least the Older People's NSF itself. Following the publication of this report we will be writing to all local authorities and health boards to ask them to provide an action plan of how they intend to address the issues we have raised. All action plans will be published on our websites.

We intend to follow up the issues highlighted in this report as part of our routine inspection programmes and will work in liaison with the Older People's' Commissioner and Board of Community Health Councils in so doing. HIW's programme of unannounced dignity and essential care spot checks will be expanded and rolled out more widely across Wales.

¹¹ *'Dignified Care? The experiences of older people in hospital in Wales'* was published by the Older People's Commissioner in Wales in March 2011

¹² The Board of Community Health Councils was established by the Welsh Government in 2004 to advise CHCs with respect to the performance of their functions; to represent collective views of councils on an all-Wales basis; and to promote collaborative working and information sharing.

Chapter 1: Introduction and background

“There is no pleasure worth foregoing just for an extra three years in the geriatric ward” [John Mortimer]

1.1 The above quote by John Mortimer although written many years ago strongly resonated with the service users we spoke to as part of this review and with the vision, principles and purpose of the National Service Framework (NSF) for Older People in Wales.

1.2 The NSF is a key strand of work to arise from the Strategy for Older People in Wales published in 2003. The Strategy emphasised the importance of engagement, participation and empowerment of older people and the need to support the ongoing contributions of older people to society in general, and families and communities in particular. It also recognised the importance of enabling older people to live their lives as actively and independently as possible in a suitable and safe environment of their choice.

1.3 A simple interpretation of the vision and aims of the NSF in relation to health and social care would be:

‘To ensure that as we advance through the stages of the ageing process health and social care services:

- *facilitate us all to enjoy life to the full;*
- *provide us with the treatment, care and support we need as early as possible so that we can live as independently as possible for as long as possible;*
- *enable us to make informed choices and options about our future;*
- *work with us to support us to live where we choose to live and where possible to avoid admission to hospital; and*

- *ensure that when we do need to be cared for in hospital we are treated with dignity and respect and with our independence maintained.'*

1.4 The NSF was developed in recognition of the fact that as we move into the next decade the need for an improvement in the services and support available for older people will be of paramount importance. Of the four UK countries, Wales has the highest proportion of people of state pensionable age (SPA). Given the advances in public health and medicine, the number of people resident in Wales aged over 85 is projected to more than double in size by 2031 (to 156,000)¹³. Such a change in the demographic profile will bring new challenges as we will see more and more people living for longer with more complex health and social care needs. In particular it is anticipated that by 2021 the number of people in Wales with dementia will have increased by 31%¹⁴.

1.5 Further, the NSF aims to address the needs of people from the age of 50 years onwards. It recognises that preparation for a healthy, active and independent old age needs to start early. It seeks to build on good practice and facilitate the sharing of innovative and effective practice to the benefit of all older people. Above all it emphasises that as a society we must recognise the right of older people to make individual choices about their care, who provides it and where care is delivered and that it is based on the individuals' personal needs.

The purpose of the review

1.6 A commitment was made by the Welsh Government to commission a fundamental review of the NSF after two years to assess progress so that its future direction and development could be informed. Therefore the aim of the review was to answer one fundamental and simple question:

¹³ Older People's Well-being, Monitor for Wales, Welsh Government, 2009.

¹⁴ Dementia UK, 2007.

‘What impact is the NSF having on the quality of life of older people in Wales?’

1.7 To answer this question the Care and Social Services Inspectorate Wales (CSSIW) and Healthcare Inspectorate Wales (HIW) worked together over a period of two years to gather, assess and evaluate available information. A key aspect of this review was the gathering of the views of service users and their families and so Age Alliance Wales (AAW) was commissioned to facilitate service user and carers’ events across Wales. A summary report from these events can be found at www.hiw.org.uk and www.cssiw.org.uk¹⁵. The outcome of these consultations has been fundamental to our assessment of progress, identification of noteworthy practice and recommendations for what needs to happen next.

1.8 The work undertaken in support of this review also involved a number of other work streams including stakeholder events involving service users and carers, commissioners as well as providers of services throughout Wales. Unannounced hospital visits and the issue of GP questionnaires were also included. A summary of the various work streams can be found at Appendix A. The ten NSF standards can be found at Appendix B.

What we focused on

1.9 A key concern highlighted very early on in the planning and scoping of this review was the increasing numbers of people who have dementia and the widespread view that often dementia is not diagnosed early enough and appropriate treatment is often not given. Such were the concerns that we decided to look at the application of the standards set out in the NSF through the ***‘lens of someone with dementia.’***

1.10 The role of the health and social care systems in meeting the multiple needs of people with dementia is a key policy issue in Wales. Numerous Welsh Government

¹⁵ Age Alliance Wales Report: Welsh Government National Services Framework Review Project.

reports including '*Fulfilled Lives, Supportive Communities*'¹⁶ and the recent Social Services paper published by the Welsh Government¹⁷ refer to particular pressures emerging in dementia care. The report '*Reviewing Social Services in Wales 1998-2008*'¹⁸ lists '*providing good options for people with dementia*' as one of the ten weakest areas identified in joint reviews undertaken by CSSIW and the Wales Audit Office.

1.11 In the following chapters we have aimed to set out our findings against the steps in the '***journey of progression and care***' that someone with dementia may travel. We have tried to describe that journey in the context of what the service users, carers and family members told us they have experienced and what they should expect. In each section we have also attempted to highlight noteworthy practice as well as gaps that currently exist in services.

¹⁶ A Strategy for Social Services in Wales over the next decade. *Fulfilled lives, Supportive Communities*. Published by the Welsh Government February 2007.

¹⁷ Sustainable Social Services for Wales: A Framework for Action. Published by the Welsh Government June 2011.

¹⁸ *Reviewing Social Services in Wales 1998-2008. Learning from the Journey*. Joint publication by Care and Social Services Inspectorate for Wales and Wales Audit Office. Published in June 2009.

Chapter 2: Health promotion, well-being and prevention

‘The physical and emotional health and well-being of people over 50 should be promoted through strong partnerships, with the aim of extending healthy life expectancy and quality of life.’ [NSF Standard – The promotion of health and well-being in older age]

2.1 As we grow older our body starts to fail us; we can no longer do the things we once did with ease, everything takes a lot longer and our immunity to certain diseases and illnesses becomes weakened. For most people retiring from work is a major event but for many it can lead to increased isolation and a real escalation of frailty and confusion as individuals become less and less active. In recognition of these issues the NSF set out the above standard relating to the promotion of health and well-being in older age.

2.2 In setting the context of the above standard the NSF makes reference to the Welsh Government’s Healthy Ageing Action Plan for Wales¹⁹ (2005) [the Plan]. The Plan brings together in one document health promotion initiatives for older people and provides evidence based guidance on health promotion interventions for older people. It recommends that across Wales action is taken forward in each of the following areas:

- physical activity;
- healthy eating;
- emotional health and well-being;
- stopping smoking;
- sensible drinking;

¹⁹ Healthy Aging Action Plan for Wales, A Response To Health Challenge Wales, Welsh Government, 2005.

- sexual health;
- home safety and warmth;
- influenza immunisation; and
- opportunities for raising awareness and general health screening for older people.

2.3 The promotion of health and well-being as well as the prevention of chronic illnesses and those related to older age is a key issue for health and social care organisations. They have a key responsibility and role to play in encouraging individuals to take responsibility for their own well-being, for promoting better health and helping older people to lead the lifestyle of their choice for as long as possible. Therefore, as part of this review we looked to see how well progress is being made in the implementation of health, well-being and prevention schemes across Wales. In particular we spoke to those over the age of 50 to see how aware they were of schemes in their area and to identify any barriers to their involvement and participation.

Physical activity

2.4 Physical activity has many recognised benefits, including positive effects on flexibility, bone density, mood and well-being. It can lower the risk of heart disease, help control blood pressure and weight problems and improve balance so avoiding and preventing trips and falls. Studies have also shown that taking part in physical activity twice a week for up to 30 minutes reduced the risk of developing dementia by half.

2.5 In recognition of these benefits and the fact that not enough older adults get involved in such activities the Plan set a series of actions for local authorities and health boards including the piloting of a free swimming scheme and the further development of Green Gym and Walking Schemes.

2.6 We found that in response many leisure centres across Wales have introduced the '*Free Swimming Initiative*' whereby during selected sessions people aged 60 and

over are able to access swimming pools for free. A number of leisure centres also offer sessions with an instructor each week for free. These include aquafit sessions, swimming lessons, stroke improvement sessions and aquagym workouts. Sport Wales manages the delivery of these free swimming sessions on behalf of the Welsh Government.

2.7 In addition, a number of community-based exercise classes and groups have been developed across Wales over the last few years. Those who utilise these groups told us how beneficial they found them not only in terms of helping them to maintain and improve their fitness but also in relation to reducing their isolation and improving their social life. A number of local authorities run community day centres which provide activities from bingo to old time dancing. Also, Age Cymru has invested in community and older people's groups and in many Communities First²⁰ areas partnerships have invested in light exercise classes and walking groups. These classes and activities provide access to social and exercise activities to many who would otherwise have not got involved.

'I don't know how I would survive without my swimming and Tai Chi classes. They get me out of the house and I feel much happier and healthier since I have been going. They give me the opportunity to meet up with others who are living alone like me and I have met many new friends.'

2.8 We found the level of engagement from health and social care organisations in the provision of exercise classes and activities to be variable across Wales. While Health, Social Care and Well-being Strategies are in place across all areas of Wales there is often an over reliance on the third sector for the provision of the drive and funding for health promotion and well-being activities. Sometimes health and social

²⁰ Communities First is the Welsh Government's programme to improve the living conditions and prospects for people in the most disadvantaged communities across Wales.

care organisations do not see the funding and running of exercise classes and activities as being core to their business.

2.9 Health boards tend to invest more in activities for those who have already suffered a stroke, heart attack or who have an on-going mental health problem. Those accessing such services told us that often the 'free' provision is only for a short period of time even when they have really benefited from the activity and that they are often unable to afford the cost of the activity when it is no longer provided 'free' of cost.

2.10 A key message to arise from the workshops we held with stakeholders was that often classes and activities are not that well publicised and so those who would benefit from them most are sometimes unaware that they are going on.

Healthy eating

2.11 According to an Age UK report (Still Hungry to be Heard)²¹, malnutrition affects 32 per cent of those aged 65 years and above. Eating a healthy and balanced diet is key to a healthy and long life. Often older people have a poor diet due to habits picked up during a busy work life or due to the financial pressures that arise following retirement. A poor diet is linked to many illnesses and chronic conditions including stroke, heart disease and obesity. Also, a poor diet impacts on well-being and one's ability to recover from illness.

2.12 In 2006 the Welsh Government introduced the '*Increasing Dietetic Capacity Grant Scheme*' across Wales to fund dieticians and support workers to train and develop community workers, peer educators and volunteers in food and nutrition skills. The original focus of this scheme was on people working with children and young people. However in 2007 the Welsh Government and the Food Standards Agency Wales awarded grants to two NHS Trusts to pilot an extension of the Dietetic Capacity

²¹ Still Hungry to be Heard was published by Age UK and can be accessed on their website at: <http://www.ageuk.org.uk/get-involved/campaign/malnutrition-in-hospital-hungry-to-be-heard>.

Grant scheme to meet the needs of older people. Two community dieticians were appointed to work in two of the more deprived areas of Wales for a three-year pilot project. They have worked with key agencies and health professionals in contact with older people, as well as with care home staff, to provide training on the identification of risk, prevention, and treatment for malnutrition. At the time of writing an evaluation of the pilot was yet to be completed.

2.13 Food Vision, a project run by the Chartered Institute of Environmental Health²² has developed a toolkit for the *'Nutrition of Older People in the Community.'* The toolkit is intended to help local authorities, and other interested organisations, understand the importance of ensuring older people in the community have healthy, safe and balanced diets. It aims to give a better understanding of the issues related to nutrition for older people in their own homes and provides ideas as to how, and with whom, practical steps can be taken at a local level to ensure healthy diets are possible and practical. All those involved in providing nutrition and guidance to those older people living in the community would find this toolkit useful in developing their plans and approaches.

2.14 At a national level there are a number of initiatives in place to promote healthy eating but local projects are fundamental to driving improved nutrition. Those contributing to this review told us of the importance of lunch clubs and food cooperatives in relation to ensuring that they maintained a healthy diet. Many of those living on their own said that often *'cooking for one'* doesn't motivate them to cook and so the social aspect of lunch clubs are key to them eating well. Wrexham Lunch Club has produced a good practice guide which organisers of lunch clubs or those considering setting up such a club would find useful.

'Who wants to cook and eat on their own? Lunch clubs are great, I get a good meal and the opportunity to chat to friends.'

²² Founded in 1883, an independent organization representing the interests of the environmental health profession.

2.15 As with many other community-based initiatives and services where they are in place, lunch clubs and food cooperatives were considered to work well and to contribute greatly to improved nutrition. Sadly however we were told they are not available in all parts of Wales and that in some areas transport issues sometimes prevent those who are most isolated and vulnerable from attending.

2.16 The Plan advocated that free transport schemes to supermarkets be reviewed and the feasibility of free delivery investigated. We came across little evidence of such schemes being put in place and given that transport was an issue for many of those we consulted with, we consider this an area where further work is needed. Where schemes had been put in place; for example, the Flintshire based '*Food Solutions Project*', which is available to anyone aged over 50, they are working well and are making a difference. This '*Shop and Drop*' service offers internet based shopping, using local supermarkets to supply older people in their own home.

2.17 While our role is not to promote private businesses and companies, so many of those that worked with us on this review highlighted the benefits they have received from engaging with Wiltshire Farm Foods. This national company makes and delivers ready meals and desserts, with a focus on nutrition.

Emotional health and well-being

2.18 As referred to in the introduction to this report, as we grow older and give up work we can become more and more isolated. We can become less confident and the mild anxiety or depression that we may have lived with and managed all our lives can escalate unless appropriately managed at an early stage.

2.19 Activities such as lunch and exercise clubs referred to above also help decrease isolation and improve confidence and emotional well-being. However, sometimes individuals will need specialist support and advice to help them through a particular crisis or due to bereavement. For example, The Plan called for increased bereavement

support to be provided across Wales through the use of the new Bereavement Helpline Wales, developed by Cruse Cymru. However, at the time of writing, this is not yet available 24 hours a day, seven days a week.

Stopping smoking

2.20 There are health benefits to stopping smoking at any age as it is a major risk factor for heart disease, stroke, respiratory illnesses and dementia. There has been a proactive campaign in Wales to help people stop smoking with television adverts and a dedicated helpline run by NHS Direct Wales to help people who wish to give up smoking. The free phone helpline is available from 7am to 11pm, seven days a week and offers help to all ages.

2.21 We have found that often in relation to smoking and the use of alcohol many healthcare professionals do not always take a proactive approach to encouraging older people to stop. Also, older people tend to be more resistant to help; how often have we heard the words:

'It's my only pleasure. I haven't got many left' or 'it hasn't done me any harm so far.'

2.22 Often people are under the misconception that by the time they have passed 50 it is too late to stop as the damage has been done. Many of the people we spoke to, while aware of the links that smoking has to cancer, respiratory and coronary heart disease, were not aware of its impact in relation to forms of dementia such as vascular dementia. More awareness raising is needed in this area.

Sensible drinking

2.23 Excessive alcohol consumption is an established risk factor for many chronic conditions and illnesses and in particular depression and dementia. The Plan

highlighted that the proportion of older people drinking over the recommended limit (up to 14 units per week for women and up to 21 units for men) has been increasing steadily since 1984.

2.24 Work that we have taken forward in relation to substance misuse has highlighted that it is often difficult to identify whether an older person has an alcohol or drug related problem. They often drink in private and alone; their symptoms of alcohol/drug abuse are often mistaken for confusion and frailty.

2.25 There is a need for frontline staff working in the community, A&E, minor injury departments and ambulance staff to be provided with training and assessment tools to help them better identify and deal with substance misuse in older people.

2.26 We have also identified that individuals often do not know where to go to get help and support when they are ready to address their problem and find accessing services difficult. Service users told us that sometimes GPs are unsympathetic and don't understand that:

'You just can't quit on your own.'

2.27 Also, they felt that health and social care professionals in contrast sometimes put all their problems down to alcohol and didn't refer them for screening and testing for other illnesses that their symptoms may be due to.

Sexual health

2.28 The Plan acknowledged that there are ageist attitudes in relation to older people and sexual health which present a barrier to older people discussing their sexual issues.

2.29 Research undertaken in relation to sexual issues and older people has highlighted that like other age groups there are sexual risk takers in the over 50

age-group and that awareness and knowledge of HIV/AIDS and Sexually Transmitted Infections is poor. Professionals therefore have an important role in educating older people about sexual health, particularly on ways to avoid problems before they arise which may impair fulfilment and have a long term impact on their health.

2.30 However, disappointingly the '*Sexual Health and Well-being Action Plan for Wales 2010-15*²³', makes little reference to the needs of older people other than to acknowledge that they were a group that needed special consideration. In taking this Action Plan forward reference needs to be made to the Older People's NSF.

Home safety and warmth

2.31 The '*Keep Well This Winter*' Campaign is a Welsh Government initiative that is coordinated by Age Cymru and supported by a range of national organisations.

2.32 The campaign is delivered locally through events and activities that are organised by partners such as Public Health teams, Age Concern, Care and Repair, other voluntary organisations and local authorities. The Stay Healthy at Home project run in the Monmouthshire area is one example of the schemes put in place to help manage amongst other things the risk of falls at home.

Influenza immunisation

2.33 Influenza circulates each year in the UK during the winter months (October to April). It is often called seasonal flu due to there being slight changes to the virus each year which means that some people who encounter the new virus may no longer be fully immune.

²³ The '*Sexual Health and Well Being Action Plan for Wales 2010-2015*' was published by the Welsh Government in November 2010

2.34 A vaccine (the 'flu jab') is offered free to everyone over 65 and people in certain 'at-risk' groups who are more likely to develop complications as a result of having flu.

2.35 Uptake in those aged 65 years and over was 66% during 2010-11. This is below the Welsh Government's new target of 75% but is an increase of 2.2% from the uptake recorded for 2009-10. Our discussions with stakeholders highlighted that often the vaccine is not taken up due to a lack of awareness and concerns that the vaccine has side effects.

Opportunities for raising awareness and general health screening for older people

2.36 Those who contributed to our review told us that they had some knowledge of some awareness campaigns but they were not sure as to the total number of screening and testing services available and how to access them. A campaign that was noted as being a particular success is the FAST campaign for the early detection of stroke. The television campaign and visual messages have had an impact and helped improve the recognition of the symptoms and signs which often complicate an ischemic or haemorrhagic stroke:

- **F**acial weakness – can the person smile? Has their mouth drooped?
- **A**rm weakness – can the person raise both arms to shoulder height?
- **S**peech problems – can the person speak clearly and understand what you say?
- **T**ime to call 999.

2.37 There are three all-Wales screening programmes established to improve the health of the people of Wales that all older people should have the opportunity to access:

- Bowel Screening Wales;
- Breast Test Wales; and
- Cervical Screening Wales.

2.38 In addition, while there are no nationally organised screening and testing programmes for:

- prostate cancer;
- diabetes;
- cholesterol; and
- blood pressure

such screening and testing should be routinely provided by GP practices. Again the picture across Wales was mixed with some participants providing us with examples of holistic health screening by their GPs and others reporting that they had never had their blood pressure checked.

2.39 Disappointingly, despite us issuing a questionnaire to all GP practices in Wales asking them for information in relation to the care they provide to older people on their list we got very few completed returns. The feedback provided to us by those who use GP services is that they felt that more could be done by GPs to enhance their health and well-being.

Chapter summary

2.40. One of the key aims of the Older People's NSF is to keep us healthier in older age. The NSF therefore promotes more proactive and systematic health checks for older people and the provision of community-based activities that encourage a healthier lifestyle and emotional well-being.

2.41 The provision of coordinated and holistic health promotion and prevention services is of fundamental importance to the quality and dignity of us all as we grow older. They can help us to stay well and keep living life the way we want to for longer.

2.42 Our review has highlighted that across Wales a number of innovative and valuable services and support mechanisms have been put in place. We were told that schemes and services that worked well were:

- exercise and activity classes;
- lunch clubs;
- shop and drop internet services such as the Food Solutions Project in Flintshire; and
- television adverts such as the FAST advert for stroke.

However, there is variation in provision and in many areas there are still gaps. In particular more needs to be done to:

- coordinate and advertise activities locally;
- support those older people with substance misuse issues; and
- address the sexual health agenda for older people.

2.43 Knowing what services are available and what you are entitled to can make practical and positive differences to your day-to-day life. At a local level, we found it difficult to find out what services are available and when, and were told by stakeholders that this was often a problem for them. For example, we sampled a number of local authority and health board websites and found that it was nearly impossible to find information on older people services and groups on many of them. Rhondda Cynon Taf County Councils website was one of the exceptions with the front page clearly signposting information for older people. A number of local authorities in collaboration with health boards issue a newsletter which is delivered to every house in their area.

We were told that such newsletters are key to providing information to those who live alone and are isolated.

2.44 Greater investment is needed at a local level in health promotion, prevention and community services if we are to help and support people to live healthy and longer lives. This is the biggest dilemma for statutory agencies as the impact and benefits of such investment for them will not be immediate but longer term. They need to work more closely with the third sector to see how together they can put a cohesive approach to promotion and prevention in place. In recognition of the fact that Wales requires a step change in its approach to developing both policy and service delivery models for primary and community care the Welsh Government published '*Setting the Direction*²⁴.' This sets out a framework to assist statutory agencies to develop and deliver improved primary care that is proactive, coordinated and focused on prevention.

²⁴ Setting the Direction, Primary & Community Services Strategic Delivery Programme, Welsh Government, 2010.

Chapter 3: Maintaining independence at home for as long as possible

‘Health and social care services treat people as individuals and enable them to make choices about their own care. This is achieved through the unified assessment process, integrated commissioning arrangements, the integrated provision of services and appropriate personal and professional behaviour of staff.’ [NSF Standard – Person centred care]

3.1 When first diagnosed with dementia most people will be living at home either with family or alone. As their condition progresses they will require varying and sometimes fluctuating levels of support and intervention to help them manage their condition and to maintain their independence for as long as possible. It is fundamentally important that health and social care agencies, both statutory and third sector, work together to ensure a holistic service that is focused on the needs of the individual and his/her carer. By working together agencies can help support individuals to live in their own homes, if they so wish, for longer.

3.2 While there are indications that the quality of domiciliary services are improving, there is a continuing need to ensure that those who provide personal care to people who have dementia receive appropriate training. The need for improved training in relation to dementia has been acknowledged by the domiciliary care sector. The United Kingdom Home Care Association²⁵ is taking forward work in this area.

3.3 Service users and their families told us that often services are fragmented and do not provide support for their holistic needs. As emphasised in the introduction to this

²⁵ United Kingdom Homecare Association Ltd (UKHCA) is the professional association of home care providers from the independent, voluntary, not-for-profit and statutory sectors.

chapter, joint working and collaboration amongst statutory and third sector health and social care organisations is key to addressing this issue. This needs to start with agencies across sectors working together to understand the demographic, prevalence and trends information for their local area. They must also understand the needs and preferences of those with dementia and their carers if they are to provide the services that are needed and which will work well.

3.4 While we note that some joint commissioning strategies are in place, they are variable and the quality of supporting protocols in place are also variable across Wales. The working protocols in place with primary health care providers are few and communication and coordination across agencies and sectors needs to be improved.

3.5 It is clear that health, social care and third sector organisations need to work better to provide holistic and integrated services that are timely and meet the needs of individuals. The Self-Assessment Audit Tool (SAAT) issued in support of the Older People's NSF is designed to enable local partners to jointly monitor and assess their progress. Currently the SAAT is being used to support the submission of information to the Welsh Government; organisations need to recognise that it is an important evaluative tool that should be used universally to benchmark performance.

3.6 An unanimous message from service users and carers was that statutory organisations should engage better with third sector organisations in the provision of support and services. Third sector organisations in turn told us that they felt that often their contribution is seen as '*optional*' and they are not always asked what contribution they could make. A number of service users and carers told us of their concern that due to many third sector organisations relying on short term grants and charitable funds, the services that they value and require could be taken away from them.

3.7 We believe that statutory health and social care organisations should be realistic in terms of what they themselves can and cannot provide. They need to be open to the

idea that many third sector organisations are better at providing certain services and work with them to ensure holistic and patient centred care.

***‘Older people who have a high risk of developing mental health problems and others with related diagnosis have access to primary prevention and integrated services to ensure timely and appropriate assessment, diagnosis, treatment and support for them and their carers.’ [NSF Standard –mental health in older people]
(Including dementia in younger adults)***

Assessment and diagnosis

3.8 The *‘NICE-SCIE Guideline on Supporting People with Dementia and their Carers in Health and Social Care’* (2007) states that population studies suggest that cognitive impairment is observable several years before an individual is diagnosed with dementia. Individuals may have mild cognitive impairment for a number of years that they and those close to them put down to *‘normal’* ageing.

3.9 Early recognition of cognitive impairment, diagnosis and intervention is key and can delay the progression of illness. It can also help individuals and their families to manage the illness better, dispel any anxieties, and allow for planning for the future when the illness may progress at pace.

3.10 To enable early diagnosis the public and professionals must be able to recognise the signs and symptoms. Our review highlighted deficits in awareness amongst the public and health and social care professionals of the signs of early onset of dementia. A number of those we spoke to told us that they had gone back and fore to their GP for a number of years and had been prescribed medication for depression before they were later diagnosed with dementia. The timeliness of diagnosis was a real concern for many of the people we spoke to.

‘It was extremely difficult for me to get a diagnosis and after repeated visits to my GP I paid to see a private consultant.’

‘My GP told me I was getting older and it’s to be expected.’

3.11 We are pleased to note that in recognition of the need to improve dementia awareness, the Welsh Government’s ‘Book Prescription Wales Scheme²⁶’ has been expanded to include four books on dementia. This will improve patients’ access to appropriate, more detailed information, with books recommended by health professionals and which can be accessed free of charge across Wales via the public library service. The Welsh Government is also working with the Alzheimer’s Society²⁷ to run a national awareness campaign.

3.12 Reaching a diagnosis is often a long process involving various steps and professionals. Those we talked to told us that they often felt ‘*bombarded*’ by assessments and were confused as to what the different tests and assessments were about.

‘My assessment was like a maths exam.’

3.13 They also told us that often they felt that they had to repeat the same information over and over again leading to them questioning whether information was being shared.

3.14 The NICE-SCIE Guideline states that memory assessment services should be the single point of referral for all people with a possible diagnosis of dementia. These services should ensure an integrated approach to the care of individuals with dementia and support for their carers.

²⁶ Book Prescription Wales is a scheme that aims to help people with mild to moderate emotional problems to make use of high quality self-help books that have been specially selected by psychologists and counsellors working in Wales.

²⁷ Alzheimer’s Society is a membership organisation which works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland.

3.15 A *'How to Guide: Improving Dementia Care'*²⁸ has been produced as part of the 1000 lives plus²⁹ campaign. This provides guidance on the establishment of memory clinics and clearly states that such services should ensure timely diagnosis allowing earlier intervention and reducing the time between onset of symptoms and diagnosis being communicated. All health boards should ensure that they assess their memory services against the guide and should take part in the *'Royal College of Psychiatrists Memory Services National Accreditation Programme'*³⁰, or at least self-assess their services against the published quality standards.

3.16 Those we spoke to were very positive about their experiences in relation to memory clinics. They found them extremely useful in terms of signposting to information and services and providing support to carers. However, we were told that in certain areas of Wales due to capacity issues there are waiting lists which lead to delays in diagnosis and interventions. Also, there is variation in the size and structure of these clinics leading to inequality in services across Wales.

Delivering the news

3.17 Telling someone that they have dementia is a difficult and unenviable job but clinicians need to be open and honest. They also need to discuss disclosure carefully with the patient and ensure that there is clarity in relation to what the person wishes to be told and who the person wishes information to be shared with. Those we spoke to said that the period leading up to their diagnosis had been stressful and concerning for them and their family.

'My GP either didn't know or didn't want to say.'

²⁸ *'How to Guide: Improving Dementia Care'* was published in 2010 to enable healthcare organisations and their teams to successfully implement a series of interventions to improve the safety and quality of care that their patients receive.

²⁹ 1000 Lives Plus is a national programme which seeks to improve the quality of patient care and reduce avoidable harm across NHS Wales.

³⁰ The Memory Services National Accreditation Programme works with services to assure and improve the quality of memory services for people with memory problems / dementia and their carers.

3.18 The Dementia Services Development Centre Wales³¹ has been commissioned by the Welsh Government to increase the training capacity and expertise in Wales. Training will be provided to primary care staff including GPs and this will help support GPs to not only identify the signs of dementia better but also to deliver what is devastating news in a supportive way.

‘A range of enabling, community-based services are available to intervene promptly and effectively when older people’s independence is threatened by health or social care needs, with the aim of challenging dependency and maximising well-being and autonomy.’ [NSF Standard – challenging dependency]

3.19 It is important that independence is promoted and supported throughout the various stages of dementia; although the level at which it can be maintained will vary throughout the various stages.

‘As her illness progressed I wanted to wrap her in cotton wool. It became painful to watch her struggle to do the things that she once did with ease and so I started to do them for her. I soon realised that this was not helping her and the only one benefiting was me.’

3.20 Health and social care professionals need to work with individuals and their families/carers to ensure that their personal care, social, leisure and spiritual needs are appropriately addressed; so that their quality of life and dignity is maintained throughout their journey. Families and carers need to be supported to enable them to assist individuals to maintain an active life.

³¹ Bangor University and the Service Development Team (EMI) in Cardiff work in partnership to provide, on an all-Wales basis, a Dementia Services Development Centre. DSDC Wales ensures that initiatives and good practice in Wales are disseminated to the rest of the UK and vice versa.

3.21 Community Mental Health Teams (CMHTs³²) have a key role to play in the provision and coordination of support and care for those with dementia who are living in the community. As part of this review we visited a random sample of CMHTs from across Wales and spoke to staff about the role of the CMHT in dementia care. We found staff to be committed to providing a holistic and patient centred service.

3.22 We also reviewed a number of case files to assess what care had and is being provided by the team. We found that a disappointing number of cases reviewed showed no evidence of a joint assessment or of the unified assessment process being followed; despite a requirement for the approach to be fully implemented by October 2006. The purpose of the Unified Assessment (The Single Assessment as it is known in England and Scotland) is to bring together a coordinated approach to health and social care assessment. We also found that sometimes different risk assessment processes are being used by health and social care staff. This finding accorded with the feedback from service users and their carers:

‘Unified assessment – if only.’

3.23 Joint assessments by health and social care staff are of key importance if un-fragmented and patient centred care is to be provided. The needs of an individual with dementia and his/her family will fluctuate over time and CMHTs need to be able to offer and provide a range of responsive and effective services. They should serve as a central contact for the person with dementia and liaise with all other agencies on their behalf. However, our visits highlighted that provision varies from area to area and that there is a particular gap across Wales in relation to therapeutic and psychological provision in community teams. This is disappointing, given the emphasis placed by the NICE-SCIE Guideline on the importance of therapeutic interventions.

³² Community Mental Health Teams deliver health, social care and psychological interventions together with medical treatment, which take account of an individual’s range of needs.

3.24 People with dementia and their carers told us they generally found information and support through voluntary services only. Also, people with dementia and their family carers do not feel sufficiently involved in the development of their care package. Many carers and relatives told us that they did not feel valued and 75% of those involved in focus groups coordinated by Age Alliance said that they had not been given any choice. In addition, 70% of participants said that they had never accessed social care and hence relied on family members. They said that they felt that Social Services should contact them and ensure communication throughout their journey of progression.

3.25 We were also disappointed to find information technology systems in health and social care that do not complement each other; consequently there is duplication of records and business functions.

3.26 On a positive note, some CMHTs have introduced dementia support worker posts which are proving to be extremely valuable. These posts provide support to people with dementia and their carers, helping them to maintain their independence, improving their sense of well-being and putting them in more control of their lives. They also assist people with dementia and their carers to identify their needs and access services.

Hearing and eye sight tests

3.27 Individuals with dementia need to have their hearing and eye sight checked on a regular basis as these senses are important to maintaining good communication; which is in turn key to effective support and intervention.

3.28 The necessary communication aids need to be used to ensure that the person with dementia is given the opportunity to understand what they are being told rather than it being assumed that it is their dementia preventing them from understanding.

The work we have taken forward with RNIB Cymru³³ and Action on Hearing Loss Cymru³⁴ has highlighted that hearing loops, translation services, sign language services are often not available or used.

Activities of Daily Living (ADL) skills training and cognitive behaviour therapy

3.29 The NICE-SCIE Guideline advocates that ADL skills training and cognitive behaviour therapy can promote independence in personal care tasks such as dressing, washing and feeding and help individuals manage their symptoms and behaviour. Such training can enable individuals to have more control and also reduces the stress on carers. The training involves carers in the development of an individualised training programme.

3.30 Disappointingly, none of the service users we spoke to had been involved in such a training programme. It is clear that there is a shortage of community-based occupational and psychological therapy support, which needs to be addressed if Wales is to see improvements in dementia care.

3.31 The principles of ADL should be used to develop activity plans that involve the individual and their carers. A wide range of activities should be put in place that are varied and ensure that the individual is integrated with his/her local community. Those we spoke to told us that they valued lunch clubs and the activities coordinated by organisations such as the Alzheimer's Society. They did however point out that sometimes activities were not suited to them and they felt that they just had to fit in.

³³ RNIB Cymru works on behalf of over 100,000 people in Wales with sight loss and campaigns for the inclusion of people with sight loss.

³⁴ Action on Hearing Loss Cymru (formerly known as RNID Cymru) provides support for people with hearing loss and tinnitus in Wales

'My wife arranged for me to go on a trip through my memory clinic. When I got into the minibus I realised that I wasn't going to have the jokes and laughs I thought I would have, as the others' dementia was far more advanced than mine. I felt isolated and for the first time realised where I was heading.....I never went on a trip again.'

Adaptive aids

3.32 Adaptive aids do not only help with memory loss but also help to manage trips and falls as well as other safety issues. Small changes to the home environment such as visual prompts, signs, calendars, schedules can help improve outcomes in terms of independence and reduce stress for carers.

3.33 The picture across Wales appears varied in terms of the support for full assessments of a person's needs in this area. Those we spoke to told us of delays in aids being provided and many said that such aids, when provided, were to support their physical needs rather than their memory needs.

Telecare

3.34 Telecare involves a range of services including home security, alarms and reminder systems. Such technology is particularly useful in ensuring a timely response to falls and aid in keeping an individual at home for longer.

3.35 Equipment is provided to support the individual in their home and tailored to meet their needs. As well as responding to an immediate need, telecare can work in a preventative mode, with services programmed to monitor an individual's health or well-being. Often known as lifestyle monitoring, this can provide early warning of deterioration, prompting a response from family or professionals. The same technology can be used to provide safety and security through bogus caller and burglar alarms.

3.36 Telecare is being piloted across Wales and many local authority areas have demonstration houses in place where individuals can go to test out the various technologies that are available. This is a growing area where investment in technology is as much about the philosophy of dignity and independence as it is about equipment and services.

'My watch alarm is great. It looks like a normal watch so no one knows that I am wearing an alarm and I feel more confident when I am out and about on my own. I would never have ventured into the garden before in case I fell and no one would know.'

Support for carers

3.37 The pivotal role that carers play and the value that they bring to ensuring that individuals live a fulfilled life at home for as long as possible should not be underestimated. The carers we spoke to told us that they are happy to sustain their role of caring but they need to be supported to do this.

'Being able to have an afternoon for myself every other week makes all the difference. I don't need much more at the moment but know that without it I would struggle.'

3.38 Carers are entitled by law to have their needs assessed in their own right. In 2009-2010 the needs of 5,916 adult carers across Wales had an assessment or review of their needs and as a result 2,755 were provided with assistance³⁵. In 2010-11 the number of adult carers in Wales increased by 494.

³⁵ Figures taken from Statistics Wales, 2009-10.

3.39 In July 2010 the Princess Royal Trust for Carers³⁶ and the National Mental Health Development Unit³⁷ published '*The Triangle of Care - Carers Included: A Best Practice Guide in Acute Mental Health Care*³⁸.' The guide emphasises the need for better local strategic involvement of carers and families in the care planning and treatment of people with mental ill-health and recommends better partnership working between service users, their carers and provider organisations.

3.40 The '*Triangle of Care*' approach was developed by carers and staff to improve carer engagement in acute in-patient and home treatment services. The guide outlines key elements to achieve this, examples of best practice and extensive resources to help people working with carers to involve them more effectively in acute care services.

3.41 The carers we spoke to told us that sometimes they felt forgotten and struggled to get statutory agencies to communicate and coordinate with them. They said that they found carers support groups, such as Alzheimer's cafes where they can just drop in and have a chat with others in the same position, to be invaluable.

'Some days things just get to me particularly if the weather is bad. The Alzheimer's café provides a welcome break. I only wish it was open every day.'

3.42 Often those with dementia will need to access respite care. We found the range and quality of specialised respite services to need further development. Currently respite provision, out of hours support and weekend day care is inadequate and more needs to be done to achieve the aim of maintaining independence at home for as long as possible .

³⁶ The Princess Royal Trust for Carers was created on the initiative of Her Royal Highness the Princess Royal in 1991 to provide carers with support.

³⁷ The National Mental Health Development Unit (NMH DU) was launched in 2009 to provide national support for implementing mental health policy by advising on national and international best practice to improve mental health and mental health services. NMH DU closed on 31 March 2011.

³⁸ The Triangle of Care - Carers Included: A Best Practice Guide in Acute Mental Health Care published by the Princess Royal Trust for Carers and the National Mental Health Development Unit on 28 July 2010.

3.43 Good quality respite care provided either in an individual's own home, at a care home or at a community hospital facility, at a time to suit the carer, can aid people with dementia to live at home for longer. However, many of the carers we spoke to felt that the level of respite care they were offered was too little and often it could not be pre-arranged. In many cases we were told that respite was only offered when they had got to crisis point.

'I didn't want him to go into hospital and had been asking for a night sitter for weeks. In the end I had no choice as I was so tired.'

3.44 Some carers raised concerns with us about the quality of respite care and told us that they had seen a decline in the general health and well-being of the individual they cared for following a respite stay. One carer told us that a two week respite stay had turned into a two month ordeal.

'Older people are enabled to gain maximum benefit from medication to maintain or increase their quality of life.' [NSF Standard – Medicines in Older People]

3.45 Four out of five people over 75 are taking at least one prescribed medicine³⁹. Medicines should only be prescribed when it is considered that they will enable the individual to maintain or increase their quality and duration of life and in particular for those with dementia medication should not be used as an alternative to good therapeutic interventions. For example, for many types of dementia such as Lewy Bodies the use of atypical antipsychotics should be avoided due to the possibility of severe side effects.

³⁹ Figures taken from the National Service Framework for Older People in Wales, 2006.

3.46 We used prescribing data compiled by Health Solutions Wales ⁴⁰(December 2009) to look at the level and trend in the usage of six classes of drugs commonly used amongst the older population for dementia and other mental health related disorders. These included Antidepressants, Antimanic, Antipsychotic, Anxiolytics, Control of Epilepsy and Hypnotics.

3.47 The data highlighted areas of Wales where the prescribing of drugs for mental disorders such as '*anxiolytic*' drugs (commonly prescribed for anxiety) is higher. However, these areas seem to be particularly old industrial valleys of South and South East Wales, which may reflect social conditions and physical morbidity as there is a history of social deprivation and therefore this association may be not unexpected.

3.48 We also noted that the prescription of '*hypnotic*' drugs was significantly higher in North Wales than in other areas. It is recommended that hypnotic drugs and anxiolytics are only used in the treatment of individuals with dementia for short courses of treatment due to the risk of individuals becoming dependent on them.

3.49 Some of the people we spoke to told us that they had not been given adequate information regarding their medication and possible side effects. They highlighted concerns in relation to the fact that they had little or no understanding of what each tablet does and that changes are not monitored effectively. It would appear that improvements are needed in terms of both patient involvement and the frequency and effectiveness of medication reviews.

3.50 Given the anomalies and questions raised in relation to prescribing practices across Wales we will be undertaking further work in this area over the coming year.

⁴⁰ Health Solutions Wales is part of the NHS Wales Informatics Service (NWIS) and provides a range of specialist information, information technology, telecommunications and consultancy services to the NHS in Wales

Chapter summary

3.51 From our consultations with people with dementia and their carers and relatives it is clear that those with dementia do not always receive good person centred care. Quite often care is fragmented and reactive rather than proactive and responsive. There were however, signs of progress and improvement with most of the health and social care professionals recognising the need to change practice and work together. For example, as part of the Welsh Government's Invest to Save Initiative, a £9 million support package was granted to the 'Gwent Frailty Programme' in September 2010. This Programme is looking to create an integrated model of care that is community based. The Gwent Frailty programme is just one example of innovative approaches being taken forward across Wales.

3.52 Health and social care organisations need to listen to what users of services are saying, which is that: *'People with dementia are individuals, with individual needs, likes and dislikes. Their uniqueness must be understood and respected and this was not always their experience'*⁴¹.

3.53 Providing care to people with dementia often in the later stages of their lives can be both difficult and demanding. Comprehensive care planning that includes all the available information about the service user and their preference for care is important. In a recent King's Fund report⁴² 75% of those surveyed said they wanted to choose where they were treated, yet less than half said they had been offered a choice. This accords with the Age Alliance work undertaken as part of this review; 75% of participants expressed frustration at the lack of choice and dependency on traditional services.

⁴¹ A preliminary analysis of Dementia in Wales. Published by the Care and Social Services Inspectorate for Wales in July 2010.

⁴² Patient Choice, How Patients Choose and How Providers Respond, King's Fund, June 2010.

3.54 Recent statutory guidance aimed at ensuring greater consistency in charges for non residential social services will hopefully result in a fairer and more affordable approach to the provision of services. It should also help to rebalance services towards prevention and early intervention, and in so doing help improve people's choices.

3.55 It is clear that the third sector have a lot of experiences and skills to offer and all health and social care organisations need to work together and identify where they can best influence and improve services. Also, primary care practitioners and in particular GPs need to be better engaged in a team approach to care and support as their role is critically important in ensuring access to appropriate and timely assessment.

3.56 Awareness and training of health and social care staff and the public in relation to the signs and symptoms of the early stages of dementia is key to ensuring early and timely intervention. Also, if we are to help those with dementia live happy and fulfilled lives for as long as possible we need to look to interventions that are therapeutic in nature and only turn to medication where it has a clear therapeutic benefit or is absolutely necessary.

Chapter 4: Maintaining independence while in hospital and ensuring that people are not discriminated against because of age.

***'When admission to hospital is necessary for older people, the care they receive is coordinated, efficient and effective in meeting their clinical and non-clinical needs.'* [NSF Standard – Hospital Care]**

Specific issues for older persons' mental health wards

4.1 People with dementia should be assessed and treated as far as possible at home and only in extreme circumstances admitted to hospital for assessment. Reference is made in the NICE-SCIE Guideline to less than 1% of people with dementia requiring treatment in an in-patient unit; however for this to become a reality the issues outlined in previous chapters need to be addressed.

4.2 The reason for any admission to hospital should be made clear to carers and relatives and plans should be put in place to ensure an efficient and timely discharge. Admissions should be for as short a time as possible.

Environment of care

4.3 It is important that the layout and size of in-patient units is conducive to a therapeutic environment of care. The design of environments for people with dementia should support orientation and minimise confusion. To avoid frustration and anxiety wards should have tactile way-finding cues, good lighting and windows that allow daylight to enter.

4.4 Good practice states that large multi-purpose rooms and long dead end corridors should be avoided as they give an institutional feel to wards. Colour and pictures should be used to help with orientation and clocks and calendars should be visible to remind individuals of the time and date.

4.5 Environments should be homely and stimulating and individuals should be encouraged to bring favourite pictures and belongings in with them. There should be easy and safe access to outdoor space so that individuals can get fresh air safely. Given the complexity of patients' needs, wards should ideally have no more than 12 beds.

4.6 As part of this review we visited a number of older people's mental health wards. While staff were noted to be doing their best to make patients comfortable, few wards provided good therapeutic environments. A number of wards were based in old district general hospitals and were not designed for the care of older people with dementia. While some of the newer units provided a better environment, some provided difficulties with winding corridors and individuals tending to be cared for in one large room during the day. The wards were often very clinical, with bare walls and no stimulating pictures or murals.

4.7 A key theme arising from stakeholder events and our dignity and respect spot-checks was mixed sex wards. Although all the wards we visited had single sex bays, we found that some of the toilet and bathroom facilities were being used for both sexes.

Staff mix

4.8 Given the complexity of needs (usually those individuals with dementia also have co-existing physical or medical problems) wards should be staffed by a mix of mental health and general nursing staff. We found that the majority of older people's mental health wards are staffed by mental health nurses, which means that some medical care

may not be possible on the ward, and so patients have to be moved to general wards which can be very upsetting for them.

4.9 Our work in relation to monitoring of the Mental Health Act has highlighted the need for better physical medical care input into mental health wards. We found that as a result medical issues sometimes go undiagnosed or treated. We identified weaknesses in the arrangements in place across all health boards with only one having a written policy in place that covered the provision of medical care for those receiving care on a mental health ward.

4.10 The NICE-SCIE Guideline recommends that older people's mental health wards are overseen jointly by physicians for the care of the older and old age psychiatrists. It is reasonable to expect that the care that older people receive should be coordinated, efficient and effective in meeting both their clinical and non-clinical needs.

Stimulation and therapies

4.11 In 2001 a study⁴³ was conducted on fifty patients with moderate to severe dementia. These patients were randomly assigned to either Multi-Sensory Stimulation (MSS) or activity sessions over a four week period. The study showed that MSS and structured activity sessions had an immediate, significant benefit for patients with dementia. They were less bored, spoke spontaneously, related to others better and were more alert and attentive to their environment.

4.12 However, we found that the amount and range of therapies and activities provided for patients throughout the day on many of the wards we visited as part of our dignity and respect spot-checks to be poor. One patient told us that:

'There is nothing to do all day and it is very boring sitting by the bed.'

⁴³ Barker et al (2001). A randomised control trial of the effects of multi-sensory stimulation (MSS) for people with dementia. British Journal of Clinical Psychology, Volume 40, Issue 1.

4.13 Some of the wards we visited have appointed 'Refocus Nurses' who are responsible for planning daily activities for the patients on the ward. These nurses assess each patient and identify suitable activities to be incorporated into their care plan so that they are kept occupied and stimulated.

4.14 All wards should have input from occupational therapists, speech and language therapists, physiotherapists and psychologists. It is important that during their in-patient stay individuals are properly stimulated and encouraged to maintain their independence. However, our visits highlighted that input from therapists and psychologists is limited and we saw few examples of well developed activity programmes. Many people told us how frustrated and bored they had become when in hospital and told of how they felt that their in-patient stay had exacerbated their memory loss and confusion, rather than help it.

'When I first went in to hospital I complained to my family about the number of patients who just kept walking up and down the corridor. Within a week I had joined them.'

4.15 Ward staff do their best to provide activities and make days fun for patients and during our visits we noted examples of staff going above and beyond to compensate for the gaps in formal provision.

Issues for all wards

4.16 A study undertaken by the Alzheimer's Society⁴⁴ has shown that the outcomes for those with dementia who are admitted to hospital are markedly poorer than those without. The study demonstrated that people with dementia have a higher risk of needing long term residential care and dying following their admission than people

⁴⁴ The Journal of Quality Research in Dementia Issue 8, The Care of People with Dementia in General Hospital, Bart Sheehan, Chris Stinton and Kate Mitchell.

without the condition. During their time in hospital they are also at high risk of developing major complications such as pressure sores, falls and incontinence.

4.17 The decisions that are made about and for this group of people while they are in hospital can have long-term consequences for their quality of life and staff face dilemmas in balancing risks, autonomy and health care resources.

4.18 Evidence from the stakeholder groups we spoke to, as well as research across Britain, suggests that many health and social care professionals involved in the planning or delivery of care to people with dementia do not have the appropriate training and level of awareness needed. There is a need for awareness training for professionals working on general wards as for example, older people treated in general nursing beds in hospital told us that there was a lack of understanding of their needs resulting in their physical needs being met but their psychological needs being overlooked.

4.19 HIW has recently undertaken a review of reciprocal arrangements across medical and mental health wards and this has highlighted some skills deficits leading to older people with mental health problems on general wards not always having their mental health needs met. There is clearly a need to ensure that the right skill mix of staff is available so that people with dementia have access to the specialised care they need wherever they are being treated in a hospital.

4.20 A recent study undertaken by the National Confidential Enquiry into Patient Outcome and Death⁴⁵ has looked at elderly patients who died in hospital within 30 days of undergoing surgery. They found that only one-third of elderly patients were judged to have received good care with most patients being admitted as emergencies by very junior doctors without timely input of senior care of the elderly clinicians. The study also found that poor nutrition and serious associated illness were very common in the group

⁴⁵ An Old Age Problem, A Review of the Care Received by Elderly Patients Undergoing Surgery, a report by the National Confidential Enquiry into Patient Outcome and Death, 2010.

studied and clinically significant delays occurred for one in five patients between admission and their operation.

Care planning and continuity

4.21 We reviewed a sample of care plans during our visits to wards and found that they often lacked detail and did not address holistic needs. Many people with dementia and their carers and relatives told us that they had not been sufficiently involved in care planning and were often unclear as to the detail contained in care plans. Many told us that they felt disempowered and considered that:

‘Staff seemed to think that they knew my needs better than my wife and I. They behaved as though I was incapable of doing anything and wanted to do everything for me. Why couldn’t I have a bath on my own?’

4.22 We were told that often the next step in progression and care came as a surprise as these had not been discussed or agreed with individuals.

Capacity

4.23 **‘Capacity’** is a person’s ability to make a decision. The Mental Capacity Act 2005 states that the starting assumption must always be that a person has the capacity to make a decision, unless it can be established that they lack capacity. The Act also states that a person’s capacity must not be judged simply on the basis of their age, appearance, condition or an aspect of their behaviour.

4.24 However, during recent dignity and respect spot-checks on wards where there were older people with a mental health condition which might affect their ability to make decisions, we found many of the systems for assessing and recording capacity to be poor and not well documented and staff knowledge of these issues and patient rights to be variable.

Dignity and respect

4.25 Many individuals and their relatives and carers told us that they felt that staff on both older people's mental health wards and general wards needed further training in customer care and communication. They felt that staff often talked down to them and did not pay them the respect they deserved. They felt that some staff were over-familiar and automatically called them by their first name or a pet name without asking how they wanted to be addressed or were patronising in their attitude.

'When she started calling Elizabeth I looked around the room and suddenly realised she meant me. I hadn't been called that since childhood. I soon realised that I had come off lightly as she called the lady sat next to me and said come on deary.'

4.26 Many older people were very concerned that they had no choice over the gender of nurse who cared for them. A number of ladies told us that they found it upsetting and humiliating to be bathed and dressed by a male nurse. They said that they felt they should be asked their preference or whether they had a problem with being cared for by a male nurse.

'Until my recent admission to hospital the only man to see me in my underwear was my husband. I couldn't believe that a male nurse was going to bathe me. The staff thought I was being difficult and silly when I said I would prefer to go un-washed.'

4.27 Continence was a major issue for many individuals. They told us of how they had gone into hospital continent and within days were being given continence pads. It appears that too often continence pads are being used instead of taking time to toilet individuals regularly. This is a very important issue in terms of maintaining independence and ones dignity and staff should work with individuals to maintain continence.

Privacy and confidentiality

4.28 A number of concerns were raised with us about consultations taking place behind curtains where everyone could hear the discussion. Also, people said that they disliked white boards and their names being displayed on the door to their room. They felt that a label might as well have been put around their neck.

Fluids and nutrition

4.29 The '*All Wales Nutritional Care Pathway (2009)*⁴⁶' sets out the approach to the nutrition screening of patients on admission and the pathway for good nutrition care throughout their hospital stay. The pathway is supported by the '*All Wales Food Record Chart*' and '*Daily and Weekly Intake and Output Charts*,' with accompanying posters giving pictorial illustrations of various portion sizes to standardise record keeping across Wales.

4.30 However, despite such guidance being in place, a number of concerns were highlighted in relation to fluid and nutrition. Some people with dementia and their carers told us that they were rarely regularly weighed while in hospital and had never had fluid and nutrition input and output charts completed. Such monitoring is of key importance to those who are older and more vulnerable as they can quickly become dehydrated and malnourished; this in turn impacts on their ability to fight off illness and maintain organ function.

4.31 One carer told us of her experiences when her husband went in to hospital for a period of respite. She explained:

⁴⁶ The '*All Wales Nutritional Care Pathway*' was introduced by the Welsh Government in 2009 as part of a range of initiatives to improve food and drink in hospitals.

'He started to eat and drink less and less and then suddenly he started to deteriorate. We were told to expect the worst as his kidneys had started to not function.'

4.32 Patients also told us that they didn't feel there was enough time to eat food at their own pace and they had little support and encouragement from staff to eat and often trays were taken away with food being untouched. The availability of snacks was variable and meal times were found to be too rigid.

'I drove my wife mad when I came out of hospital I had to have my dinner and tea at specific times. I hadn't realised I had become so institutionalised.'

4.33 The recent Wales Audit Office Report '*Hospital Catering and Patient Nutrition*⁴⁷' identified a number of concerns in relation to the nutritional value of meals, the use of the red tray system and protected meal times. Health boards need to carefully consider this report and act on its recommendations.

Cleanliness and infection control

4.34 Cleanliness and infection control was a particular concern for stakeholders. In particular, they highlighted that patients were rarely offered the opportunity to wash their hands after using a bedpan or commode.

4.35 A number of individuals told us that they had been unable to shower or bath as often as they did at home because they had to wait to be helped by a nurse. They said this led to them feeling under-valued. Concerns in relation to oral hygiene were also raised.

Communication

⁴⁷ Hospital Catering and Patient Nutrition, Wales Audit Office, March 2011.

4.36 Communication aids for patients with a sensory impairment were unavailable on most of the wards that we visited. This lack of support can lead to feelings of isolation, loneliness and frustration as patient needs are not fully met and a lack of stimulation has been found to escalate dementia. Also, one has to question how assessments of capacity and cognitive competency can be undertaken without such aids.

4.37 Often those with dementia will revert back to using their childhood language as their condition progresses. Studies have shown that this is often due to the part of the brain that deals with language skills becoming affected. It is important that where this occurs, information, assessment and care is provided in the individual's original language of choice.

Recognising protection of vulnerable adults issues

4.38 The relatively low Protection of Vulnerable Adults (PoVA) referral rates from primary and secondary healthcare providers raises questions about the level of understanding of NHS staff around what constitutes a safeguarding issue and in particular what is abuse. The responsibility of health professionals in relation to the safeguarding of vulnerable adults starts as soon as the individual is admitted into their care and does not stop when that individual is ready for discharge. Also, as we have said in previous reports poor care, when it occurs, can be itself regarded as neglect or even in extreme circumstances abuse and should be dealt with as a PoVA issue.

4.39 Conversely, the position with regard to PoVA in social care appears to be more embedded in practice as indicated through higher levels of cases being referred.

4.40 Clearly, health and social care professionals have a continuing responsibility to ensure that appropriate and safe care and discharge arrangements are put in place.

Planning for discharge

Intermediate care is established as a main stream, integrated system of health and social care which:

- enables older people to maintain their health, independence and home life;
- promptly identifies and responds to older people's health and social care needs, helping to avoid crisis management and unnecessary hospital or care home admissions; and
- enables timely discharge or transfer from acute hospital settings to more appropriate care settings which promote effective rehabilitation and a return to independence. [NSF Standard – Intermediate Care]

4.41 Issues relating to maintaining independence and home life and avoiding unnecessary hospital or care home admissions have been covered in earlier chapters. In this section we have therefore focused on arrangements for discharge.

4.42 A National Audit Office study undertaken in 2007, '*Improving Services and Support for people with Dementia*⁴⁸', found that people with dementia are estimated to account for over half of those people who remain in hospital unnecessarily. Intermediate care and rehabilitation beds, which could take patients who no longer need acute care, often explicitly exclude people with dementia.

4.43 While there are some excellent examples of coordinated care and discharge planning, often there are gaps and shortcomings. Both health and social care professionals told us that decisions around continuing health care can be difficult and challenging. In particular, there are shortfalls in residential and nursing home capacity

⁴⁸ Improving Services and Support for people with Dementia. Published by the National Audit Office July 2007.

for those who have complex needs, which can lead to delays in transferring patients to the appropriate care setting. The further development of collaborative commissioning and planning between health and social care, coupled with an effort to unlock resources from traditional services, is the best way of tackling this challenge.

4.44 We have been alerted to a number of incidents where older vulnerable people have been discharged from hospital at inappropriate times of the day to unsafe home environments. For example, one older lady told us that she was discharged from an acute hospital late on a Friday afternoon to a home that had no heating, where there was no food and no family or support services available to ensure her well-being. Sadly, this is just one example of a number of similar stories related to us by patients and carers.

4.45 Planning for discharge should commence prior to any elective admission and immediately upon any emergency admission. However, we have noted many instances when discharge planning has been delayed due to late and uncoordinated care planning. This has wide implications for the individual as well as having a financial impact on the NHS. People should not stay in hospital longer than is necessary – it is not a place for well people.

Chapter summary

4.46 People train to become doctors and nurses because they want to care for people. A key message that has come out of this review is that sometimes *'caring is translated into doing to and for.'* It is important that healthcare staff remember that they have a key role in supporting individuals to maintain their dignity and independence as long as possible. A key aspect of this is involving them in every aspect of their care and empowering them to make informed choices and decisions.

4.47 Long hospital stays can have an impact on independence and confidence whatever your age or diagnosis but for those with dementia the potential impact is greater and so any hospital stay should be avoided unless there is a very real clinical need. When admission is necessary health and social care staff should work with the individual, carers and relatives to ensure a timely and well planned discharge.

4.48 The provision of a therapeutic environment and stimulating activities should form part of the routine on older people's wards and care and support should be holistic.

4.49 The findings set out in this chapter have been shared with the Older People's Commissioner for Wales as part of the evidence gathering for her report on '*Dignified Care?*' We hope to work closely with the Commissioner and the Board of Community Health Councils to ensure that the experiences of those with dementia are improved.

Chapter 5: Conclusions and next steps

5.1 In our review we looked at seven of the ten NSF standards using the pathway of an individual with dementia; to enable us to provide an answer to a key question - ***‘What impact is the NSF having on the quality of life of older people in Wales?’***

5.2 It can be said with certainty that the NSF has had an impact. It, together with related strategies and the role of the Older People’s Commissioner for Wales, has raised the profile of older people in Wales and highlighted the need for them to be treated as individuals and without discrimination. All those who participated in our review valued the focus that the NSF has brought to the need to think innovatively and outside of the box when providing care and support to older people.

5.3 However, the full implementation and consequent benefits of the NSF are still a long way off. Health and social care still have a lot to do in terms of refocusing their approach and agenda to one of prevention and empowerment.

5.4 The National Dementia Vision for Wales⁴⁹, launched by the Welsh Government and the Alzheimer’s Society in February 2011 recognises many of the issues highlighted in this report. It identifies four priority areas:

- improved service provision through better joint working across health, social care, the third sector and other agencies;
- improved early diagnosis and timely interventions;
- improved access to better information and support for people with the illness and their carers, including a greater awareness of the need for advocacy; and
- improved training for those delivering care, including research.

⁴⁹ The National Dementia Vision for Wales was launched on 16 February 2011 by the Welsh Government and the Alzheimer’s Society. It highlights the support and advice available to anyone diagnosed with dementia.

5.5 The guidance necessary to address the issues raised in this report is therefore already in place. Now what is needed is a period of consolidation with a strong focus on implementation rather than writing more policies, strategies and NSFs.

5.6 A certain degree of bravery is needed by statutory health and social care agencies in being honest in their assessment of what they are good at and not so good at and then doing something about it. They need to look more to third sector agencies to help them drive this agenda where they can better provide what older people need.

5.7 There is an inherent tension between a preventative approach and an eligibility framework that targets the highest needs as priority. This must be tackled if service providers are to deliver early intervention to support the independence of people in need of support and although this report is based on dementia it is equally applicable to all chronic conditions that affect older people such as respiratory disease and diabetes.

5.8 Collaboration between health, local authorities and third sector organisations is needed to help to deliver the changes needed. This important agenda cannot be achieved by organisations working alone or in parallel. Future services must be able to respond to the holistic needs of older people living with dementia.

Next steps

5.9 We started to pull together a long list of recommendations to be issued with this report and realised that we were just repeating what has already been said in various strategies and reports, not least the Older People's NSF itself. Following the publication of this report we will be writing to all local authorities and health boards to ask them to provide an action plan of how they intend to address the issues we have raised. All action plans will be published on our websites.

5.10 We intend to follow up the issues highlighted in this report as part of our routine inspection programmes and will work in liaison with the Older people's' Commissioner for Wales and Board of Community Health Councils in so doing. HIW's programme of unannounced dignity and essential care spot checks will be expanded and rolled out more widely across Wales.

Methodology

We established five separate work streams, each with its own particular focus:

1. Service user perspective

We commissioned Age Alliance Wales (AAW) to engage with service users, potential service users and carers in order to gather their views and perspectives on health and social care services for older people in Wales, and in particular services for people with dementia. As part of their work AAW held seven consultation events across Wales and produced a summary report of the information they gathered.

2. Commissioning and Planning

We held an all Wales Commissioning workshop with the Social Services Improvement Agency (SSIA) and the National Leadership and Innovation Agency for Healthcare (NLIAH) (including the Clinical Governance Support and Development Unit). The aim of the workshop was to develop an understanding of the impact commissioning and planning groups are having on the implementation of the NSF across Wales. Particular consideration was given to how well services are being integrated across health and social care and the challenges that commissioners face.

3. Providers of care in Wales:

Social care

We commissioned Care Forum Wales (CFW) to capture information from the care home sector. CFW held a workshop in July 2010 to discuss the challenges faced by the

sector in responding to existing needs and gather their views on the building blocks that need to be put in place to meet future need.

We sought the views of the domiciliary care providers by engaging with the United Kingdom Home Care Association (UKHCA) and representatives of the domiciliary care sector in Wales.

Health care

We spoke to a number of service users to gather their views and experiences on health and social care provided in Wales. In addition, HIW carried out a programme of unannounced Dignity and Respect '*spot checks*' in a number of hospitals across Wales, paying particular attention to wards and departments providing services to older people with mental health problems.

As part of this work, we carried out interviews with staff, patients and carers; examined patient and other records and observed the environment and the care and treatment being provided. The overall findings from these visits have informed this report. The findings from each individual unannounced visit have also been published on HIW's website.

4. Health and social care pathways (CHMTs)

In early 2010, HIW and CSSIW jointly visited a number of Community Mental Health Teams for older people. Our aim was to track and assess the care pathways of service users across health and social care against the requirements of the National Service Framework. The visits covered every Local Health Board area in Wales and included interviews with staff at all levels as well as examination of patient records.

5. Primary care

Working in partnership with General Practitioners (GPs), we produced a questionnaire about the NSF and sent it to all 650 GP practices in Wales. We also undertook a statistical analysis of GP prescribing patterns of medication for mental health problems in older people.

In addition, in 2011 we carried out further desk top research covering aspects relevant to the scope of our review. This included a review of the wider work carried out by HIW, CSSIW and other inspection, audit and regulatory bodies.

Older People's National Service Framework Standards

Rooting out age discrimination

Health and social care services are provided regardless of age on the basis of clinical and social need. Age is not used in eligibility criteria or policies to restrict access to and receipt of available services.

Person centred care

Health and social care services treat people as individuals and enable them to make choices about their own care. This is achieved through the unified assessment process, integrated commissioning arrangements, the integrated provision of services and appropriate personal and professional behaviour of staff.

The promotion of health and well-being in older age

The physical and emotional health and well-being of people over 50 is promoted through strong partnerships, with the aim of extending healthy life expectancy and quality of life

Challenging dependency

A range of enabling, community-based services is available to intervene promptly and effectively when older people's independence is threatened by health or social care needs, with the aim of challenging dependency and maximising well-being and autonomy.

Intermediate care

Intermediate care is established as a mainstream, integrated system of health and social care which:

- enables older people to maintain their health, independence and home life;
- promptly identifies and responds to older people's health and social care needs, helping to avoid crisis management and unnecessary hospital or care home admission; and
- enables timely discharge or transfer from acute hospital settings to more appropriate care settings which promote effective rehabilitation and a return to independence.

Hospital care

When admission to hospital is necessary for older people, the care they receive is coordinated, efficient and effective in meeting their clinical and non-clinical needs.

Stroke

The NHS, working in partnership with other agencies where appropriate, take action to prevent strokes and to ensure that those who do suffer a stroke have access to diagnostic services, are treated appropriately by a specialist stroke service and subsequently, with their carers, participate in a multi-disciplinary programme of secondary prevention and rehabilitation and appropriate longer term care.

Falls and fractures

The NHS, working in partnership with local authorities and other stakeholders, takes action to prevent falls, osteoporosis, fractures and other resulting injuries, and to

maintain well-being in their populations of older people. Older people who have fallen receive effective treatment and rehabilitation and, with their carers, receive advice on prevention through integration of falls and fracture services.

Mental health in older people (including dementia in younger adults)

Older people who have a high risk of developing mental health problems and others with related diagnosis have access to primary prevention and integrated services to ensure timely and appropriate assessment, diagnosis, treatment and support for them and their carers.

Medicines in older people

Older people are enabled to gain maximum benefit from medication to maintain or increase their quality and duration of life.