

Colleagues it is such a pleasure to be asked to speak with you today about the implications of the new National Dementia Strategy on home care provision.

I am sure many of you will know a little about Alzheimer Scotland our main aim is to make sure that no one goes through dementia on their own and we do that by providing as much support and information as possible and by being a leading force for change at all levels in our society.

Alzheimer Scotland welcomed the strategy and we believe it is a significant step forward in tackling many of the difficulties experienced by people with dementia and their families. The strategy has been developed in partnership, and we have welcomed the opportunity to ensure that the views of our members and the people and families we represent, have been listened to and are central to the strategy's objectives.

It is unfortunate that it is only now, in such an uncertain economic climate, that dementia is receiving the necessary level of government priority. Whilst we appreciate the pressure the economic climate places on national and local government, we remain convinced that progress towards a world class dementia service would have been greatly accelerated by new money to help services to make changes. However, we are pleased that the BIG Lottery has indicated their intention to aid the development of post-diagnostic support and early intervention, this looks like it will amount to something like 5 million per year, which in this climate is a precious commodity, which we welcome and we will do all we can to assist in the effective use of these valuable funds.

We also know that the resources already committed to helping people with dementia and their families can deliver better outcomes, especially if they are personalised and utilised to better support and work with the invaluable

contribution of family members and friends, without whom we simply could not cope.

We also believe that some of the most important issues do not require additional resources: respecting people with dementia and their families as equal citizens, with the dignity they deserve, costs nothing. The strategy is built on these principles and has at its heart the rights of people with dementia and their families to support that is personalised, timely and consistent.

As many of you will know , last year we worked with the Cross Party Group on Alzheimer's to develop a Charter of Rights, the rights in the charter are built around the internationally agreed human rights and are intended to promote the respect, protection and fulfilment of all human rights for people with dementia and their families as guaranteed in the European Convention of Human Rights.

The charter was developed through extensive consultation with people with dementia, their family carers, friends and professionals. I am sure if you have signed up to it, you will agree that in the end it produced a very worthwhile charter and a PANEL model, a model which ensures that a human rights based approach is not seen as an additional burden but rather as an effective set of tools for improving policy and practice and for dealing with many of the difficult ethical issues that arise in providing support to people with dementia and their carers.

The PANEL model emphasises the principles and rights of everyone to:

- Participation - in decisions which affect their human rights
- Accountability - of those responsible for the respect, protection and fulfilment of human rights
- Non-discrimination and equality

- Empowerment - to know their rights and how to claim them
- Legality - in all decisions through an explicit link to human rights legal standards in all processes and outcome measurements

There is no stronger foundation that I can think of to build our strategy on and we believe that the full adoption of the charter in the strategy provides us with a set of principles that transcends all sectors and professions and ensures that we get it right for everyone living with dementia.

The strategy also builds on a number of existing initiatives in the statutory, independent and voluntary sectors to improve dementia care and services in Scotland and examples of these include:

- Dementia has been established as a national clinical priority by the Scottish Government.
- The Scottish Dementia Forum
- A HEAT target for NHS Boards to deliver agreed improvements in the early diagnosis and service response.
- Post-diagnostic support pilots.
- The wide distribution of a number of publications: Coping with Dementia – a Handbook for Carers; Worried about your Memory; Facing Dementia – how to live well with your diagnosis; Understanding Dementia – a Handbook for Young Carers and Taking Charge.
- The Scottish Dementia Clinical Research Network.

- Along with this we have put in place a network of 19 Dementia Advisers in 18 local authorities, and now also fund three Dementia Nurse posts in NHS Lothian, NHS Borders and NHS Ayrshire and Arran.
- And many Local authorities and health boards are developing innovative approaches to enable more people to live safely and comfortably in their homes with their families for longer and you can see particular examples of this in the strategy.

In my view the strategy is an honest appraisal of some of the real challenges we face.

It highlights five key challenge areas and addresses these by focussing on two key service delivery areas and by setting out a further eight specific actions which will support improvements in care and treatment

The five key challenges that have been identified are

1. The fear of dementia that means people delay in coming forward for diagnosis
2. Information and support after diagnosis for those with dementia and their carers is poor and often non-existent
3. General healthcare services do not always understand how to respond well to people with dementia and their carers which leads to poor outcomes.
4. People with dementia and their carers are not always treated with dignity and respect.

5. Family members and people who support and care for people with dementia do not always receive the help they need to protect their own welfare and to enable them to go on caring safely and effectively.

The two key service delivery areas in which immediate change is required are

Post diagnostic support

And care in general hospital settings, including alternatives to admission.

There are a further 8 actions to support the transformation and development of services, although it is accepted that there is no quick fix.

These are

1. the development of common standards of care for dementia based on the charter of rights.
2. The development of a skills and knowledge framework for both health and social care
3. Integrated support for change – using a “ strategic lean approach and piloting a whole system redesign in two areas.
4. Improved management and outcome information to ensure outcomes are being delivered
5. Continued work on diagnosis
6. Better response to behaviours that staff and carers find challenging including targets to reduce psychoactive medication
7. Accelerated implementation of the dementia integrated care pathways
8. Continued action to support research.

The implementation of the strategy will be supported by an Implementation and Monitoring Group, that will produce an annual report and take the lead in doing it all again in 2013.

So what are the key implications for the Home Care sector,

Well first and foremost I believe that we really need to educate the many health and social care professionals involved in dementia care and help them understand the true potential value of high quality home care.

And to understand the central part you and your colleagues play at present and will play much more in the future in the lives of people with dementia. Social care, social work and health care all need an equal place at the planning table. I am sure that many of the people you support do understand the essential role you play in keeping them safe and well and I suspect if they had control of their own budgets might choose a little more of that and a little less time with some other professionals.

However, in the current climate and with the existing modes of commissioning it seems to me that there will be many significant challenges facing us all and this will require a strong set of values and principles to guide us through. I firmly believe that task based short slot commissioning does nothing to improve anyone's dementia, that does not mean it is not valuable, in some circumstances it might be entirely appropriate and essential for some tasks that carers need assistance with, but this cannot be seen as an intervention to support the persons ability to cope with the illness. Yet it very often is regarded and indeed sold as such. I think this is wrong, I believe that when a service is provided to someone in order to help them cope with their dementia then it must do exactly that, it must be provided in a manner that is underpinned by a desire to improve that persons coping methods and daily living skills, utilising a range of memory

techniques, cognitive stimulation interventions, risk enabling and supporting the person and their family to maintain community connections and natural supports. I sincerely think that we have lost this focus and that the overwhelming view that not much can be done about dementia has permeated into our psyche and allowed us to think that basic support is all that we can do and that this is good enough.

Colleagues, I am sure you will agree that this is simply not good enough, we have a generation of people whose only contact is this basic support and who see very few other professionals unless they reach a point of crisis and need some urgent intervention.

In my view this concept of basic care need not be so basic or task orientated. Accepting this as the norm has led to it being grossly undervalued as a resource within our system of care and to the skill set of many of the good staff delivering it to also being grossly underestimated. Our system is so broken that there is no one pulling together a proper personalised and enabling plan of support for individuals with dementia and using the skilled inputs from home care staff to deliver a much more ambitious and creative form of support.

We fought hard to ensure that the principles of personalisation are part of the strategy and we will be able to make sure that they form part of the knowledge and skills framework that is to be developed and the new standards.

I am at a loss to understand why so many people think that personalisation and dementia are not meant for each other. It seems like many people view personalisation as too aspirational for people with dementia and their families. Too difficult to think about funding, not relevant for people as they go through the later stages of journey, impossible for people who lack capacity to decide.

I dispute all of this, and I believe that in fact personalisation and dementia go hand in hand with each other. I believe that there is a spectrum of empowerment methods that can be drawn upon at any stage of each person's journey and that personalisation can be a reality for everyone with dementia and their family.

Personalisation is about people being in control of their own support, and designing it around their needs, not simply fitting them into existing services. It is not complex and it is a basic human right. The strategy starts with the basic principles of human rights embedded in our charter, this naturally guides one towards the principles of personalisation as the model of practice we should all adopt, because as I said this all about human rights.

Until we realise that support needs to be far more creative, flexible and personalised we will be committing people to an early withdrawal from normal everyday life, calling it care and then organising it in such a way that the person and their family has no control over it. This has to stop.

I think the strategy offers us all the opportunity to begin to reshape and refocus our individual social care support for people and ensure that it is delivered by staff who are trained and skilled in supporting people with dementia. If local authorities pursue savings through economies of scale, people with dementia will suffer. Task-based homecare, combined with large-scale day care will add to the loss of skills, community involvement and increase demand for services such as expensive residential care and hospital admissions, as well as the human and financial cost of poor primary carer health. Short term gains found in this way will only lead to an unachievable long term cost.

In order to avoid this we are looking to the strategy to place equal importance on social care issues and on health issues. It is important to encourage local authorities to see what is possible and what can be achieved by using creative

early interventions and taking a personalised approach to commissioning social care services throughout the journey of dementia.

We recognise the current funding issues and difficult economic climate. However, the growth in the number of people with dementia is well known and cannot be addressed affordably using current approaches. We must make these changes and investments if we are to hope to meet these future needs.

In my view the strategy gives us an opportunity to come together around a rights based agenda and to challenge commissioning methods and demand a change, based on the value that we place on the skills and contribution of your staff and organisations and the difference we know we can make but the current system is not allowing us to achieve.

Human Rights are at the heart of the strategy and it is time to reclaim these rights and to ensure that we all live by them, now more than ever we need this moral compass to help us all get through these difficult times ahead. We need them to ensure that the many services we will need to fight to protect are worth fighting for and we need them to make sure that we don't allow this too easily accepted mantra of "difficult decisions" to become the excuse for any violation of the rights of people with dementia and their families to citizenship and equality.