

NORTH YORKSHIRE COUNTY COUNCIL

CARE AND INDEPENDENCE OVERVIEW AND SCRUTINY COMMITTEE

17 MARCH 2011

WORK PROGRAMME REPORT

1.0 Purpose of Report

- 1.1. The Committee has agreed the attached work programme
- 1.2. The report gives members the opportunity to be updated on work programme items and review the shape of the work ahead.

2.0 Background

- 2.1 The scope of this Committee is defined as:

'The needs of vulnerable adults and older people and people whose independence needs to be supported by intervention from the public or voluntary sector.'

3.0 Budget Issues

- 3.1 Following your special meeting on 25 November Group Spokespersons reviewed the latest position on the ACS budget savings for 2010-15 at their last Mid-Cycle Briefing. They asked that the attached schedule be included with your papers to every meeting so that if Members had any further questions on latest developments they could be raised.

4.0 National Dignity Action Day – Dementia Declaration

- 4.1 As part of National Dignity Day you agreed at your last meeting to invite Councillors and representatives of organisations the Committee has worked with to sign the Dementia Declaration.
- 4.2 This Declaration is about what people intend to do by 2014 to transform the quality of life for people with Dementia and their family carers. It was timely that the commitment was signed on National Dignity Day, "Give the Gift of Time".
- 4.3 The additional pledge people signed up to was to help North Yorkshire County Council become an exemplar authority, not just in terms of elected Member awareness of the condition but also the level of their involvement with Dementia issues in the communities they represent.

- 4.4 During discussion people expressed their views and ideas about how we can best educate people in the community to remove the stigma around Dementia, how community leaders might contribute to achieve that goal and what influence they can have.
- 4.5 Whilst it was still important that the Committee monitored service development, a change in approach to how it contributes to raising awareness might be called for. There was a danger in becoming overly concerned with structures when a more constructive agenda might be how we help Members understand the condition of Dementia and how it impacts upon individuals and families.
- 4.6 Increasingly constituents will be approaching their local elected Members for support and expect them to have an understanding of what their options are. Perhaps we could enlist the support of the Alzheimer's Society in drawing together an informal training programme. It would also be helpful for local Members to be put into contact with a society representative on their Local Dementia Forum.
- 4.7 There was a good deal of interest in the comments of the representative from the Alzheimer's Society who worked on the "frontline", particularly with children and young people. I was asked to draw your attention to the attached booklet "The Milk is in the Oven" which is seen as a useful and interesting guide for raising Dementia issues with young people, particularly in an educational environment.

5.0 Other Developments regarding Dementia

- 5.1 Since the meeting 2 further issues in relation to Dementia merit attention.
- 5.2 On Friday, 4 March, Care Services Minister, Paul Burstow announced the launch of a campaign to raise awareness of the early signs and symptoms of Dementia. A £1.2m campaign will feature on TV, radio and printouts and will be initially piloted in 2 regions, one of which is Yorkshire and Humber. If successful this will be rolled out to the rest of the country.
- 5.3 A report has also been prepared from a think-tank meeting on 16 February where people came together to consider the issues relating to "Living Well with Dementia" and the Big Society. A copy of the summary report is attached.
- 5.4 Your Chairman suggests these be raised with representatives of the Alzheimer's Society and the PCT prior to the next meeting of the Dementia Network.

6.0 Request for Scrutiny of Support for Carers: Mr D Harbourne

- 6.1 I reported to the last meeting the suggestion from David Harbourne, Chair of the Carers' Resource, Ripon, Harrogate that the Committee undertake a review of the County Council's position, strategy and plans for supporting carers in communities.
- 6.2 Rather than reach a decision there and then you asked the Chairman and Group Spokespersons to reach a view at their briefing on 24 February.
- 6.3 Their recommendation to you is that an "overview "be taken on how the County Council supports carers and their families to full Committee on Thursday 2 June, possibly Thursday 8 September.
- 6.4 In the meantime your Chairman and other Group Spokespersons will review the background, do some fact finding and research. They have yet to decide how best to approach this but to get a rounded picture of the issues carers face and how the County Council in partnership responds, they thought it might mean entering into a brief informal dialogue over the next couple of months with organisations that work with, represent and support carers .
- 6.5 I have informed David of this suggested approach and invited him to let me know if there is anything else he believes you should be made aware of and will therefore report further verbally at the meeting.

7.0 Involvement of the Independent Care Sector in the work of the Committee

- 7.1 At your last meeting you asked Group Spokespersons to review options for involving of the independent care sector in the work of the Committee. Recently Mike Padgham and Keren Wilson, in particular as representatives of the Independent Care Group, have broadened the Committee's understanding of social care.
- 7.2 Mike is coming to your meeting today to give a more detailed account of his views on how the sector will meet the challenge of commissioning in the context of the new vision for social care.
- 7.3 In the Mid-Cycle Briefing, Group Spokespersons remarked that Mike had been the Committee's main source of information on the Independent Care Sector and this had worked well. However, it need not necessarily be Mike that does that, nor should the Committee focus primarily on the Independent Care Group.
- 7.4 Whilst there was a consensus amongst Members that we should look to build upon existing relationships further, there might be additional options available to the Committee that should be explored.

7.5 I have been asked therefore to prepare a more detailed report for your next meeting on the relative advantages and different ways of involving the Independent Care Sector, ranging across the spectrum from attending as witness, as a co-opted member of a task and finish group through to the same membership rights enjoyed by the voluntary sector representatives on the Committee.

8.0 Independent Living Fund

8.1 Bridget Hardy has highlighted the possible implications of the DWP's decision to issue of the withdrawal of the Independent Living Fund (ILF). The ILF is now permanently closed to new applications.

8.2 Set up as a national resource to allow disabled people to live independent lives in their community rather than residential care, payments could be used to pay a care agency or employ someone to give personal and domestic care or both. Payments could be used for;

- Care provided by a partner or relative.
- Any care provided by social services.
- Maintaining your home or paying bills.
- Gardening.
- Adaptations to your home.
- Equipment, including wheelchairs.
- Petrol, taxi fares and other travel expenses.
- Holidays.
- Childcare.
- Private hospital or residential care home fees.
- Hairdressing, chiropody or physiotherapy.

8.3 This is not a complete list but it gives an indication of the wide range of categories the money could be used for to promote independence. The rationale for ending ILF support was part of the aim to streamline the provision of financial aid through the system of personal budgets and end confusion over where to go for support.

8.4 Group Spokespersons were of the view that the impact of the withdrawal in terms of funding and supporting independence should be looked at. There hasn't been sufficient time to prepare a report for this agenda. I have arranged for it to be discussed further at the Group Spokespersons next Briefing on 14 April. This would be the prelude to more detailed consideration, probably at your next meeting in June, on the impact of the Coalition Government's intentions for welfare benefit reform (Universal Benefits).

9.0 Recommendations

- 9.1 The Committee is recommended to consider the attached work programme and determine whether any further amendments should be made at this stage.

BRYON HUNTER SCRUTINY TEAM LEADER

County Hall
Northallerton

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8 March 2011

Background Documents: None

CARE AND INDEPENDENCE OVERVIEW AND SCRUTINY COMMITTEE - WORK PROGRAMME – January 2011

Vision for Social Care

P1. Prevention	P2. Personalisation	P3. Partnership	P4. Plurality	P5. Protection	P6. Productivity	P7. People
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In-depth Scrutiny Projects

SUBJECT	AIMS/TERMS OF REFERENCE	ACTION/BY WHOM	PARTNERSHIP ISSUES	TIMESCALES
Access to Dementia Services	<ol style="list-style-type: none"> 1. To assess local interpretation of the National Dementia Strategy. 2. To develop proposals for a good Dementia Service. 3. Preparation of a Joint Commissioning Strategy. 	<p>Follow Up Actions</p> <p>Final Report agreed by Executive February 2009</p> <p>Further work on the Dementia Declaration and elected Member involvement in local Dementia forums</p>	Network involves partners from all sectors	Decision to be taken on next phase February 2011
Valuing Employment	<ol style="list-style-type: none"> 1. To assess and contribute to our and our partners' preparedness for the implications of Valuing Employment Now. 2. What are the numbers of people with learning disability in employment in North Yorkshire now? 3. What worked/did not work in getting these individuals into employment in North Yorkshire? 4. What are the success stories from elsewhere in the country and what lessons might be brought back to North Yorkshire? 5. How do the Committee assist the Corporate County Council understand this agenda? 6. What awareness is there among other critical partners? 7. What should be the role of ACS? 	Task Group	Working with partners in all sectors to encourage a positive approach	Final Report to be agreed

CARE AND INDEPENDENCE OVERVIEW AND SCRUTINY COMMITTEE - WORK PROGRAMME – January 2011

Extra Care Development	Report to January Committee regarding objectives of review and potential Terms of Reference	To be decided	Collaborative venture involving developer and role of housing authorities	To be decided
Re-ablement	To review and report upon the shape, impact and effectiveness of reablement services that are being and/or are planned to be delivered in North Yorkshire	To be decided		Starts January 2011
Drugs and Alcohol Team	<p>Focus around the strategic assessment on the fitness of the DAAT to deliver against its core objectives.</p> <p>Review of the structure of how the corrosive effects of substance abuse in the North Yorkshire is tackled in the county area.</p> <p>Wider analysis of the balance of activity and relationship between alcohol and drug use in our communities</p>	Task Group with Corporate and Partnerships		Final report spring/summer 2011

	2011/12						
<i>Scheduled Committee Meetings</i>	3 February <i>10:30 am</i>	17 March <i>10:30 am</i>	2 June <i>10:30 am</i>	8 September <i>10:30 am</i>	10 November <i>10:30 am</i>	2 February <i>10:30 am</i>	12 April <i>10:30 am</i>
<i>Scheduled Agenda Briefing</i>	3 February <i>9:30 am</i>	17 March <i>9:30 am</i>	2 June <i>9:30 am</i>	8 September <i>9:30 am</i>	10 November <i>9:30 am</i>	2 February <i>9:30 am</i>	12 April <i>9:30 am</i>
<i>Scheduled Mid Cycle</i>	24 February <i>10:30 am</i>	14 April <i>10:30 am</i>	14 July <i>2:00 pm</i>	13 October <i>10:30 am</i>	6 January <i>10:30 am</i>	8 March <i>10:30 am</i>	24 May <i>2:00 pm</i>

Overview Reports

Overview / Update Topics							
1. Personalisation/Self Directed Support			Update				
2. Safeguarding Adults (Board)					Annual Review		
3. Early Intervention and Prevention							
4. Dignity Champion	Report Due						
5. Library Consultation	Update	Review Results					
6. Care Charging		Review Results					
7. JSNA, Adult Vision for Social Care, Big Society and Commissioning	Overview Report						
8. Learning Disabilities and Out of County Placements	Overview Report						

ACS

Analysis of ACS Budget Savings 2010-15

Service Area	Budget 2010-11 £000's	Budget Saving Proposal	2010-11 £000's	2011-12 £000's	2012-13 £000's	2013-14 £000's	2014-15 £000's	Grand Total £000's	%
Libraries and Community Services	8,373	Libraries and Community	225	1,049	500	500		2,274	27
Purchased Res. Care for Older People	22,205	Residential Placements	2,641	2,600	2,600			7,841	35
In-house EPHs	8,489	Closure of Elderly Persons Homes	188	-76	139	360	160	771	9
Home care for OP	21,988	Home Care Procurement	900					900	27
		Increased Charging	136					136	
		Reablement	908	703	1,716	1,500		4,827	
Night Service	1,036	Night Sitting Service		1,036				1,036	100
Other services for OP	3,089	Reduced day provision and meals	131	371				502	16
Carers Budgets	2,186	Reduced support to Carers	243	457				700	32
Voluntary sector funding	5,762	Reduced funding to the Voluntary Sector	275	1,390				1,665	29
Care Management & Support Functions	18,481	Management and Support	1,632	1,943	1,885			5,460	30
Services for people with Learning Disabilities	38,095	Learning Disabilities	1,000	578	-216	1,400		2,762	7
Services for people with Physical Disabilities	7,003							0	0
Mental Health Services	4,594							0	0
Other budgets (net) - incl government grants	-10,701							0	0
Total	130,600		8,279	10,051	6,624	3,760	160	28,874	22



The
milk's
in the
oven

Semi-Skimmed Milk
Pasteurised • Homogenised
LESS THAN 2% FAT

A booklet about dementia for children and young people

Mental Health Foundation



Welcome to The Milk's in the Oven

Lots of people helped with the researching and writing of this booklet. Young people said what they thought about dementia and growing older (there are comments from them throughout the booklet). Some of the families, friends and carers of people with dementia said what it was like for them knowing someone with dementia. People with dementia also contributed remarkable and moving insights to their thoughts and feelings.

This booklet was originally written by Lizi Hann and published by the Mental Health Foundation in 1998. We have updated the original version and are grateful to Alzheimer Scotland for their support in making this possible.

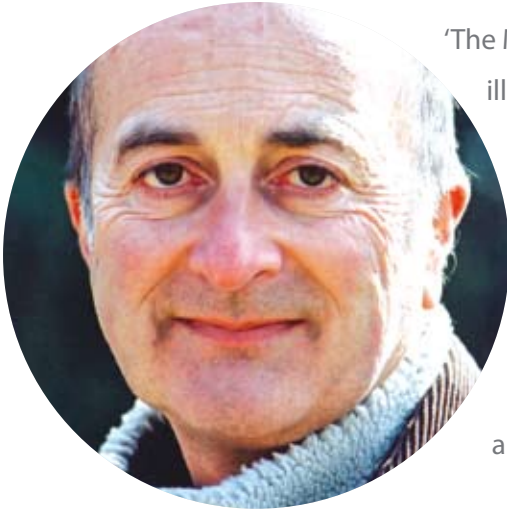


Alzheimer Scotland
Action on Dementia

Andrew McCulloch

Dr Andrew McCulloch
Chief Executive, Mental Health Foundation

Introduction by Tony Robinson



'The Milk's in the Oven' is about an illness called dementia. Although it almost always happens to older people, it's important that we all know about it. We should all try to learn what happens to people who develop dementia and think about how we can help them.

Some of you may know somebody who has dementia. Maybe they live with you and you help to take care of them. If so, you won't need me or anyone else to tell you how difficult and upsetting it can be. You want to look after people you love, but it's not easy to know what to do for the best when someone has dementia. Often people with dementia forget how to do things, so they might put the milk away in the oven, instead of the fridge. Sometimes you feel really angry because nothing you do seems to make any difference. The booklet tells you about how people with dementia behave and feel, and gives you a few ideas to try and help you understand more.





If you don't know anyone who has dementia, read this booklet anyway. Your mum or dad or a teacher might want to read it as well and talk about it with you. You might find out that one of your friends has a granny or grandad with dementia - I'm sure it would really help them to be able to talk to you about it.

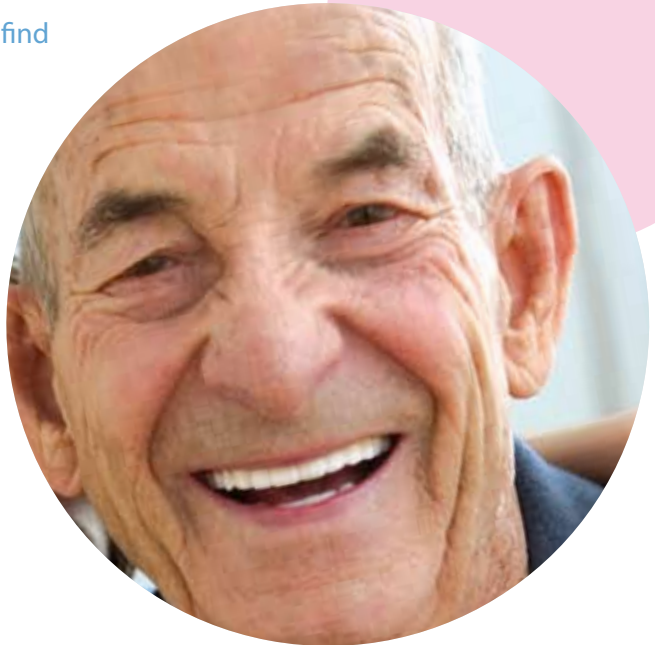
I know what it is like to live with someone who has dementia and how important it is for other people to understand. Both my mum and dad had dementia and I found the whole thing really difficult to cope with. People with dementia can act strangely. Sometimes this is quite funny, but sometimes it's frightening or embarrassing. However they behave, it's much easier to deal with if you understand why. I hope you will spend a little while reading this booklet - it'll really make a difference if you do.

Tony Robinson

What is dementia?

Dementia is caused by different illnesses which affect certain parts of the brain. When someone has dementia, they may find that:

- their memory gets worse and worse
- they become muddled and confused
- after a time, they may find it difficult to do things they used to do, like getting dressed, or making a meal.





How would you describe what memory is?

We asked some 9 and 10 year old children how they would describe memory. Here is what some of them said:

- a part of your brain that stores important things
- something that helps you remember stuff
- a store cupboard that can lose things
- a dark place with lots of things
- pictures left in my head
- a thought of the past
- fix it in my mind
- remembering

What do you mean by memory?

Memory is a very important part of all of us. It helps us to make sense of the world around us.

Our memory helps us to know who we are, where we are and what we are doing.

Our memory helps us remember things like:

- how to dress ourselves in the morning
- the names of our friends and families
- the letters in the alphabet
- where we live
- what the date is

In fact, it helps us store everything we need to know to live our lives. So, if someone has dementia they become more and more muddled and confused.





So how might someone behave if they are muddled and confused?

Often people with dementia forget how to do things - for example, they might put the milk away in the oven, instead of the fridge, or mistake the fridge for the washing machine.

They may lose their way in places they know, get dressed in the middle of the night or set off to find a place or people that they remember from the past. For example, they may think they are going off to school, as they used to do many years ago.

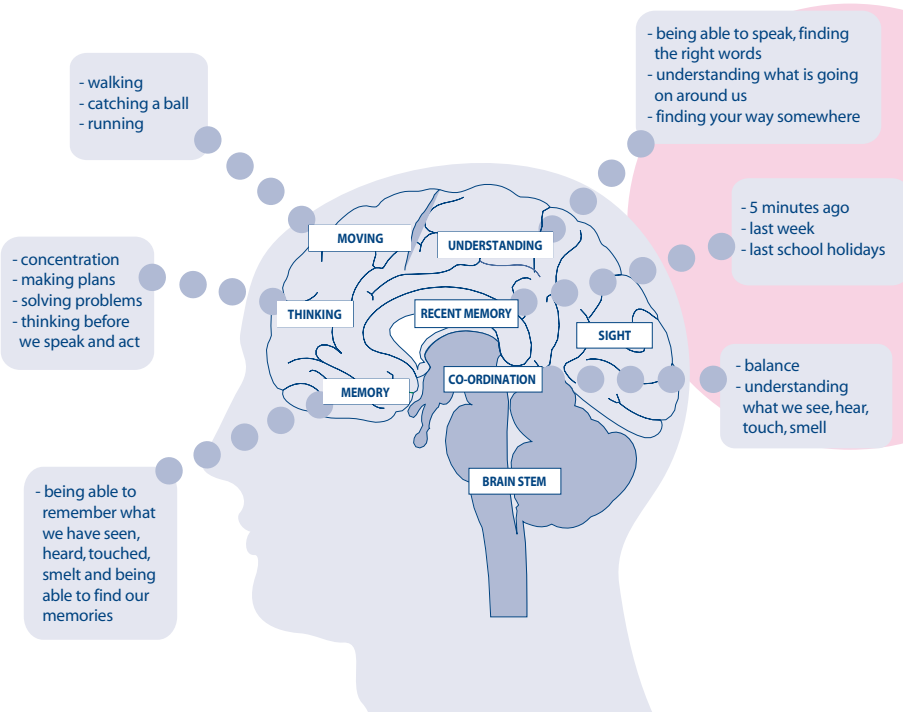


They may become confused when using things like the telephone and forget which day of the week it is.

When someone has dementia, they will find it gets harder to make sense of the world around them.

Why do people get dementia?

As you probably know, our brain is a very complicated organ. It has many different parts which help us to do many different things.



It helps us to do things like:

think, move, speak, write, play sport, play computer games

In fact, it controls everything that we do every moment of the day. So if something goes wrong with part of our brain, then we are going to find it very hard to do certain things.





Inside our brain are millions of brain cells (called neurons). When someone has dementia it is because some of these brain cells have become damaged and started to die.

Once these brain cells are dead, they cannot grow again, so this affects what the person with dementia is able to remember, think and do. This is why they find it harder to do all the different things that they used to do every day.

There are many different kinds of dementia and many different reasons why people get the disease. The different kinds of dementia have different names. If you know someone with dementia, you might hear names of different kinds of dementia and wonder what these are. It could be Alzheimer's disease (named after the doctor who first identified it), or it could be vascular dementia (named after the blood vessels in the brain which get changed).

Most people with dementia have either one of these two kinds, but there are other kinds. Mostly, the ways dementia changes people's lives are similar.

It is important to remember that people cannot catch dementia, like they can chicken pox or flu. Also, if a member of your family has dementia, it doesn't mean you are more likely to get it. Most cases of dementia do not run in the family.

Sometimes we might know what might be causing dementia, so we can try to treat the person with medicine or pills, but at other times we just don't know why the brain cells become damaged and die so that, bit by bit, the brain stops working as well as it used to. Medicine or pills may help some people for a while but they do not cure people. Scientists and researchers are doing a lot of work to try and find out why dementia happens to some people and not others.





How does someone with dementia feel?

"Nothing really makes sense to me now."

(Rachel – 79 years old – has dementia.)

This quote shows the confusion that Rachel feels.



Exercises – What does having dementia feel like?

Here are two exercises that people who are learning how to care for people with dementia sometimes do. It helps them to imagine what dementia feels like. Try it for yourself.

Exercise One:

Sit or lie down. Close your eyes. Imagine you are in the middle of a thick, thick fog. Sit still and quiet and listen to all the sounds around you. What can you hear? Maybe cars, people's voices or the television? Listen for a couple of minutes, soaking up all the sounds.

Now keeping your eyes closed, imagine that you no longer recognise the sounds, they are all coming at you in a jumble. Imagine that the volume has been turned up, that someone is spinning you round and round, and you feel frightened and confused. You don't know where you are, who anybody is and what all the sounds mean.

This is what someone with dementia can feel like.





Exercise Two:

Close your eyes again and imagine what it would be like getting ready for school when you can't remember where you put your shoes, don't know the way to school or what you are supposed to do when you get there.

Now and again it will feel as if the fog lifts and people with dementia can suddenly make sense of everything for a moment. But then the fog comes down and they feel lost again.



Here are some of the words used by people who have dementia to describe how they feel:

angry
lonely
irritable
depressed
worthless
helpless
confused
frightened
useless
embarrassed

Many people with dementia know that something is wrong, especially during the early stages. They are losing a lifetime of stored memories, and there is nothing they can do about it. So it is understandable that they feel some of these emotions.





So what might it feel like to lose your memory?



"My memory, it slims away."

We talked about memory at the beginning of the booklet. We know that it is very important to us. So what do you think it would be like if you found your memory fading away?

We asked some children "What do you think it would be like to lose your memory?"

This is what they said:

- dark, blank head
- you won't remember anything and you'll be lost
- crazy, weird

- annoying
- terrible
- sad
- good because you forget your bad memories and bad because you forget all your family
- not funny - you would miss the ones who you loved for a long, long time.



Someone with dementia might agree with some or all of the above statements. Sometimes it may well feel like they have a 'dark, blank head', and sometimes they will struggle to remember the names and faces of their family.

It is very important to remember that the person with dementia still has thoughts, feelings and emotions. But these thoughts, feelings and emotions are all jumbled up.

Sometimes they will be able to remember something that happened many years ago, as if it was yesterday, and at other times they will feel as if they are surrounded by the thick fog that we talked about at the beginning of the chapter.





Everyone who has dementia is different

“These people have lived for a long time, they have been babies, children and adults. Many have been through a world war. In their time they have seen man go to the moon, aeroplanes built, cars become part of everyday life, televisions, DVDs, mobile phones and the internet all appear.”

Psychiatric nurse

It is easy to forget that the person with dementia is still an individual. They have their own thoughts and feelings and their own ways of coping with their illness.

Let's think about you for a moment. Sit and think about these questions:

What is your favourite food?

Who is your favourite band/singer?

Which football team do you support?

What makes you happy?

What makes you angry?

What is your best subject at school?

No two people will have the same answers to all of these questions.

As you grow older, all the experiences that you have throughout your life - starting from the moment you are born - become part of your life.

These experiences help to shape your character and personality and this is what makes each of us different and special in our own way.

Everyone with dementia has their own character and personality, even if it seems hidden and changed because of the dementia. Sometimes it will seem as if they are a completely different person from who they were before, but they are not blank people with blank minds.





It's easy to forget that people with dementia have a past.

Talking to someone with dementia about their past - even for a few minutes - can give them a lot of pleasure and helps us to remember they have led a full and active life. It also helps to make their present worthwhile.

How do the people around them feel?

On the opposite page is a list of words. People who know someone with dementia have used these words to describe the way they feel.

Those of you who know someone with dementia - especially if it is someone you know very well, like your grandparent, or another member of your family - may well have felt some of these feelings yourself.

When something is different, when something happens to someone that we don't understand, we all feel confused and frightened.

When it is someone that we love, we want to help and might start to feel useless and frustrated if we can't. When the person with dementia behaves in a way that we don't expect, we can feel embarrassed, frightened or angry - and then we feel guilty for feeling all of these things!

It can be very difficult time for everyone.

Here are some of the words used to describe how people who know someone with dementia have felt:

guilty **frustrated**
helpless **embarrassed**
confused **angry**
frightened **lonely**
useless **sad**





Did you notice how similar these words are to the ones used on page 14 which describe how people with dementia say they feel?

Sometimes the person with dementia will make you feel frightened, embarrassed or angry - try to remember that they will probably be feeling the same way as you, even if they do not say so.

What can I do about these feelings?

All these feelings that we have talked about are perfectly natural. It is part of life, and part of coping with things that go wrong to feel sad, frustrated and angry.

But there are some feelings that we have talked about that we can do something about:

Feeling confused: once you have learnt something about what the person with dementia is going through, it will help you to feel less confused about why they behave the way they do.

Feeling angry and frustrated: maybe your mum and dad are spending a lot of time with your grandparent (or whoever it is who has dementia) and they don't seem to have much time for you. Remember that the situation is difficult for everyone. Your mum and dad are going to want to do everything they can for the person with dementia. Try telling them how you feel - they may have been too busy to notice and will be pleased you have told them - they have probably been worrying about you too!

Feeling embarrassed: a lot of people don't understand what dementia is, and they won't understand what you are going through. You might feel ashamed of your grandparent and not want other people to see them behaving so strangely. But remember, the person can't help having dementia, any more than if they had caught chicken pox or the flu. Maybe you could explain to your friends what your grandparent is going through and help them understand about dementia.

Feeling guilty: there are times when you might feel guilty. This might be because:

- you feel you aren't doing enough to help
- you feel like you don't love your grandparent (or the person with dementia) any more, they just irritate or embarrass you
- you just don't want to spend any time with them because it's too difficult





You can be sure that your mum and dad (or whoever is looking after the person with dementia) also feel the same way sometimes. It is difficult to like or love someone when they have changed so much, especially if they don't seem to know who you are anymore. Remember that you can only do as much as you feel able to. Talk about it - you are not alone!



Feeling useless: there is never any need to feel useless. There are things you can do to help the person with dementia - it will not cure their dementia, but it will certainly help them to feel loved and wanted.

What can we do to help?

The most important thing you can do for the person with dementia is to make a little bit of time for them.

Whether they are living in their own home, in a care home, in hospital or with you and your family, time is the most important thing that you can give to the person with dementia. And it doesn't have to be much - five minutes of sitting and chatting, or showing them a picture you have drawn, or a photo that they may recognise could make a world of difference. Here are some other ideas:

- go for a short walk together
- make a scrap book for them of past and recent events
- play music together - maybe you play an instrument, or they have a favourite record/CD that you could play
- write a simple diary together to help them remember what's happening now, something you have done together
- just sit and hold their hand for a few minutes - it can feel very comforting and reassuring to have your hand held





Of course, all these things may not be possible all of the time, and there may be days when you just don't feel like spending any time with them. That's fine too - you can only do as much as you feel like doing.

Here are some ideas that children came up with:

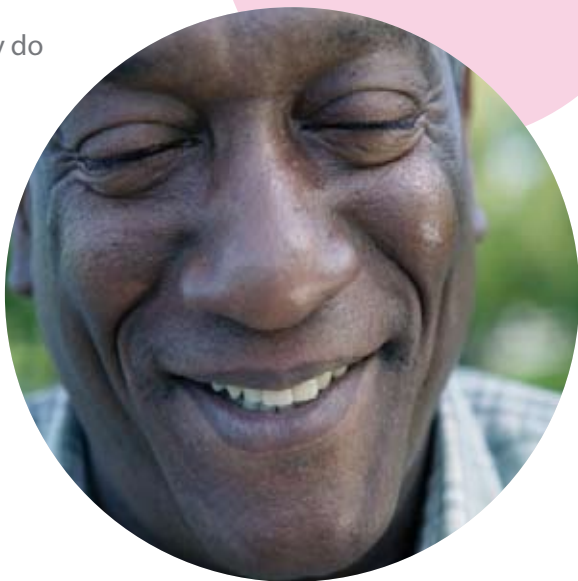
- **visit them, help with shopping - anything**
- **support them**
- **listen to them**
- **make them happy**
- **be good to them**
- **help them out - be kind to them**

But if they don't remember who I am what's the point?

Some days will be harder than others. It depends how long the person has had dementia. As the dementia gets worse they will find it more and more difficult to remember names and faces, even of their family and friends.

This can be very upsetting and you might wonder *"what's the point in spending time with them?"*

But there will be times when they do know what's going on. This could be in the middle of the night, or when they have a moment alone, or when you are with them. It will give them a great deal of happiness to know that you care about them.





For a person with dementia to know that they are loved, respected and cared for by their family is probably the most important thing in their life.



How would you like to be treated when you are older and less able to look after yourself?

No matter how old someone is or how ill, they are still a person. And even though they may not always show it, they are people with feelings - just like you and me.

We should always treat a person with dementia just as we would like to be treated when we are older.

We asked some children how they would like to be treated when they are older. This is what they said:

- looked after
- like a King
- very nicely, because I'll be fragile
- nicely, kindly
- with respect and kindness
- like a young man
- normally
- to be respected
- I would like to be treated decently
- I would like to be treated with love





Sometimes it is difficult to treat someone with respect and kindness when they have dementia. They might be rude to you, shout at you or simply not recognise you. Always remember that it is their dementia making them behave that way and that it's not your fault, and it's not their fault. All you can do is your best.



Dementia and the future

Lots is being done in the scientific and medical world to try and understand dementia and to find more ways to help people and to find a cure. Until there is a cure and a way to prevent people ever getting dementia, lots more needs to be done to help everyone understand dementia and to make sure the best kinds of help are available from family members, friends, doctors, nurses, care staff and others.

We can all try to help people who have dementia by being as understanding as we can, helping them whenever possible and telling other people what we have learnt about dementia.

Most of all though, it's important to remember that, even though a person who has dementia might act in a way that is upsetting or confusing sometimes, they are still the same person that they always were.

Exercise Three:

Who do you think needs to know about dementia?

Think of every kind of person you can.

What do you think they need to know? Try and think of everything that would help different kinds of people.





Useful contacts

AGE CONCERN ENGLAND

Astral House
1268 London Rd
London SW16 4ER
020 8765 7200

www.ageconcern.org.uk

Helpline: 0800 00 99 66

Provides advice on a variety of older people's issues, such as benefit entitlements and legal concerns. Can also help you find local support groups. Helpline open 7am-7pm every day.

AGE CONCERN CYMRU

Ty John Pathy
13/14 Neptune Court
Vanguard Way
Cardiff CF24 5PJ

029 2037 1566

www.accymru.org.uk

AGE CONCERN NORTHERN IRELAND

3 Lower Crescent
Belfast BT7 1NR
028 9024 5729

AGE CONCERN SCOTLAND

Causewayside House
160 Causewayside
Edinburgh EH9 1PR
0845 833 0200

www.ageconcernscotland.org.uk/

Helpline: 084 5125 9732

ALZHEIMER SCOTLAND

22 Drumsheugh Gardens
Edinburgh EH3 7RN
0131 243 1453

www.alzscot.org

Alzheimer@alzscot.org

Helpline:

0808 808 3000

Scotland's leading charity for people with all forms of dementia and their carers. Helpline open 24 hours.

THE ALZHEIMER'S SOCIETY

Gordon House
10 Greencoat Place
London SW1P 1PH
020 7306 0606

www.alzheimers.org.uk

enquiries@
alzheimers.org.uk

Helpline:

0845 300 0336

The leading UK care and research charity for people with dementia and their carers. Produces an extensive range of fact sheets on all aspects of dementia, and runs a national network of support groups and other services through its local branches. Its helpline is open 8.30am-6.30pm Monday to Friday, offering advice, information and support for everyone affected by dementia. Its website features a chatroom for people to exchange thoughts and feelings.

BRITISH RED CROSS

44 Moorfields
London EC2Y 9AL
0870 170 7000

www.redcross.org.uk

Offers crisis respite sitting services, to enable people who care for someone with dementia to take a break.

CHILDLINE

24 hour helpline

0800 1111

A free helpline for children and young people in the UK

www.childline.org.uk

CROSSROADS CARE SCHEMES

10 Regent Place
Rugby
Warwickshire CV21 2PN
www.crossroads.org.uk
01788 573653

Offers support for people with dementia in the home. Trained workers provide free home care.

FOR DEMENTIA

6 Camden High Street
London NW1 0SH
020 7241 8555

Tel: **020 7874 7210**

www.fordementia.org.uk

Promotes nursing care for people with dementia.





**MENTAL HEALTH
FOUNDATION**

Sea Containers House
20 Upper Ground
London SE1 9QB
020 7803 1100

www.mentalhealth.org.uk
mhf@mhf.org.uk

The leading UK charity working in mental health and learning disabilities. Undertakes research, develops services, designs training, influences policy and raises public awareness about all aspects of mental health and learning disabilities, including dementia.

NHS DIRECT

Helpline: 0845 46 47
www.nhsdirect.nhs.uk

Health information and advice service.
Open 24 hours a day.

SAMARITANS

Helpline:
8457 90 90 90
www.samaritans.org

Confidential emotional support for people who are experiencing feelings of distress or despair, including those which may lead to suicide. Helpline open 24 hours a day.

Further Reading

Dear Grandma

1999 published by the Alzheimer Society of Ireland. Available by mail order from:
Alzheimer House
43 Northumberland Ave,
Dun Laoghaire,
Co Dublin, Eire
tel: 00353 1284 6616
email: info@alzheimer.ie
web: www.alzheimer.ie
(Contains a primary school lesson plan)

What's happening to Grandpa?

Maria Shriver,
Little Brown & Co &
Warner Books, 2004
ISBN: 0-3160-0101-5

You are Words

Dementia Poems. Edited and introduced by John Killick. Published by the Journal of Dementia Care, Hawker Publications
tel: 020 77202108
email: remi@hawkerpublications.com

The Granny Project

Anne Fine,
Egmont Books Ltd, 2002
ISBN: 0-7497-4832-X

Granny's little carers

Christine Harwood,
Can be downloaded from the Alzheimer's Society website.
www.alzheimers.org.uk/news_and_campaigns/alzheimers_awareness_week/grannycarers

The long and Winding Road: a young person's guide to dementia

Jane Gilliard,
Wrightson Biomedical Publishing Ltd, 1995
ISBN: 1-8718-1631-9

About my grandfather, about my grandmother

This video shows children talking about their experiences of living and loving their grandparents who have developed a form of dementia. To arrange a viewing, please contact your local branch of the Alzheimer's Society. The video is also available to view at www.alzheimers.org.uk/news_and_campaigns/alzheimers_awareness_week/video.htm

Explaining to children

Alzheimer's Society leaflet can be downloaded at www.alzheimers.org.uk





The
milk's
in the
oven

Mental Health Foundation

Published by the Mental Health Foundation, September 2005

For more information about dementia, please visit www.mentalhealth.org.uk

To order additional copies of this booklet, please email mhf@mhf.org.uk or call us on 020 78031100

We would like to thank Alzheimer Scotland for their help in funding this publication.

Sea Containers House, 20 Upper Ground, London SE1 9QB

Tel: 020 7803 1100 Fax: 020 7803 1101

www.mentalhealth.org.uk

Registered charity No: 801130 © Mental Health Foundation

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Dementia and the Big Society

Report from Think Tank 16 February 2011

More than 40 people came together to participate in a Think Tank to consider the issues relating to living well with dementia and the Big Society.

A Think Tank is defined as a 'person or group of people, experts in some field, who are a source of ideas and who find solutions to a problem.'¹ In this instance the 'problem' is the exclusion of people with dementia from their communities, neighbourhoods and services across all sectors.

The Think Tank made no claims for putting the suggested solutions into action. It was, however, a vital first step in exploring the issues in the round and building a framework for the Big Society that will achieve inclusion for people with dementia.

The Coalition Government's 3 Big Society themes framed the discussions for the day as participants explored the opportunities and challenges in social action, community empowerment and public service reform. However, the Think Tank explored these themes from the perspective of politics with a 'small p'.

As groundwork for the Think Tank DH commissioned Innovations in Dementia to work with people with dementia in a rural area, a small town and an urban district to find out how they would define a 'dementia capable community'². A presentation of the findings from that work kick started the Think Tank.

Participants in the Think Tank included people with dementia and their supporters, community activists, providers of services across all sectors and academics (see annex a for attendance list). Prior to the event participants had read a Think Piece (see annex b) on Living Well with Dementia and the Big Society authored by Claire Goodchild and Simon Rippon who also conceived, planned and facilitated the event. A number of trigger presentations were provided throughout the Think Tank³ to offer some context and examples to the themed discussions.

This report is a summary of the discussions and ideas that emerged from the Think Tank. It does not necessarily reflect the ideas of the Department of Health, Alzheimer's Society and Bradford Dementia Group who lead Think Tank but we feel it reflects the contributions from Think Tank participants.

Summary: Key themes that emerged from the Think Tank

The 3 themes of the Big Society have much to offer people living with dementia.

¹ Chambers English Dictionary

² Dementia capable communities: the views of people with dementia and their supports

http://www.innovationsindementia.org.uk/projects_communities.htm

³ For all presentations see the homepage of www.dementia.dh.gov.uk

There is no singular solution to achieving inclusion for people with dementia. There are multiple solutions and all partners have a role to play in affecting change.

Empowering people with dementia, raising their expectations of their rights as citizens is a key step toward inclusion.

Relationships and power dynamics between people living with dementia, professionals and services are key to improving quality of services and assistance.

An assets based approach is vital to support and maintain people with dementia in their own networks, to avoid unnecessary dependence on services and to foster community development, inclusion and participation.

More conversations need to take place between people living with dementia, professionals, providers and wider society to reach a re-balancing of power and personal/community agency to promote more inclusion.

The 'art of conversations' was acknowledged as crucial for inspiring small changes that are as important as large scale change programmes

Key findings from the pre-Think Tank research with people with dementia

Innovations in dementia found that there were 5 domains for creating a dementia capable community:

- The physical environment
- Local facilities
- Support services
- Social networks
- Local groups

The five ways described how people connected to their local community are;

- Through local groups
- Through the use of local facilities
- Through walking in their neighbourhood Through the use of support services

Social action

The Coalition Government expresses social action as fostering and supporting a new culture of voluntarism, philanthropy and social action.

In our Think Piece we suggested that for dementia this means harnessing the power of social action to support and enable people with dementia to remain in their own homes, their own neighbourhoods and their social networks for as long as possible.

This would require the general public having a greater understanding of dementia and how they can support people to remain as active members of those neighbourhoods and communities.

The Think Tank heard a trigger presentation from Rosemary Hurtley, a parish councillor and community activist in Cranleigh Surrey. Rosemary outlined the inter-generational work taking place in her community that is based on positive citizenship. Kate Jones from Bournemouth and Poole Community Health presented the work they have undertaken with retailers in the Westbourne area of Poole.

We posed the following questions to Think Tank participants:

1. What can a community/neighbourhood do to support people living with dementia?
2. Who should lead community action?
3. What is the role of volunteering in improving the lives of people with dementia?
4. What can philanthropy contribute to the lives of people with dementia?

The following is a summary of the round table discussions.

The Think Tank concluded that the places where people live and engage socially are vital to a sense of well-being and belonging. Exclusion from communities and neighbourhood is all too frequently a consequence of dementia because a person often experiences reduced ability to follow the normal rules of social engagement and they can become lost or disorientated in physical spaces – this is due to marked cognitive impairments over time.

The Think Tank focused on the purpose of community and neighbourhood in a persons' life and about the desired outcomes of community action. Some of the outcomes included;

- Communities and neighbourhoods as places where people with dementia feel safe both physically and socially
- Places where other people understand what dementia is and how it affects a person so they are supported wherever they go

By 'community' the Think Tank included geographical communities (this report will sometimes use the term 'neighbourhood') as well as communities of interest.

The Think Tank acknowledged the importance of cultural sensitivity and lifestyle preferences as not everyone wants to be included in community activity and some cultures prefer to engage in family and extended family networks rather than wider community. In the same vein, some people do not want to work with the label of dementia whilst others are keen to speak openly about their dementia in order to raise awareness and to support other people with dementia. So, whilst acknowledging the nuances of a person's relationship to their community, there is still much that can be done to understand the boundaries of community and neighbourhood in this context.

The Think Tank believed there was much that communities can do to support people living with dementia and that people with dementia continue to have much to offer the community.

Permission to become socially active

It was acknowledged that some people feel the need to have permission to take social action in their community and neighbourhood. For example, some neighbourhoods do not mix socially. For many there remains a stigma around dementia and so it is often kept behind closed doors. For some people, the idea of crossing the threshold to let neighbourly support in or to offer neighbourly help is

difficult to negotiate – this may be informed by assumptions of others leading stigmatising behaviours that exclude

The Think Tank endorsed the notion that social action is a powerful catalyst for change within communities and can have a substantial impact on reform of services too.

People with dementia can play a vital role as agents of change in communities through awareness raising and volunteering but there are political issues to be addressed and these are explored in more detail on the community empowerment section of this report.

Mapping community facilities

Social action needs to be targeted to maximise its impact. One route to targeting was thought to be mapping the community facilities and social interactions of people with dementia so that it is known where people connect with their community. This links well to the work on community assets.

The mapping exercise is one that can be carried out in every community although there was support for the development of a dementia community mapping resource or toolkit. A few suggestions of how mapping could be done were offered by participants of the Think Tank;

- invite a number of people with dementia in a locality to map their use of community facilities to identify the most frequently used facilities. By joining up a number of personal maps it might be possible to link people locally who have similar interests and who can support each other in pursuing those interests.
- Place boxes in all community facilities and invite people with dementia to drop a token in the box each time they use the facility. Questions could then be asked about why some facilities are frequently used, and why others aren't. People living with dementia and those who are responsible for community facilities can then engage in a dialogue about what can happen to improve community facilities from the perspective of persons living with dementia. Providers of specialist dementia services might then have a role in supporting those improvements, to help services 'think dementia'

The Innovations in Dementia research showed that local shops are a key community touchpoint for people with dementia. The Think Tank heard from Bournemouth Community Health Trust and the local Alzheimer's Society who provide information and training about dementia to local retailers. The retailers can then pass on information to their customers about local memory services and other forms of support.

Raising awareness and understanding

Information about - and understanding of – dementia was thought to be a vital step in encouraging people with dementia to engage in social action and to encourage other people to act socially in respect of dementia.

Lack of knowledge and understanding as well as stigma are the route causes of exclusion from communities. The Government's dementia awareness raising campaign was thought to be a good start and there is much more to be done. Local engagement was thought to be necessary to normalise dementia and the Think Tank suggested a variety of ways in which this could be achieved;

- Use the Human Library⁴ project to raise awareness of dementia. The Human Library brings people together to reduce prejudice, break down barriers between people, increase social cohesion within communities by providing safe spaces.
- Intergenerational projects were thought by many participants to be key to raising awareness and understanding and simply bringing people together.
- Invite local people into services for people with dementia such as memory cafés and care homes to encourage greater understanding of dementia through learning from people with dementia.

Community readiness

The Think Tank understood that different communities are at different states of readiness to address issues of dementia.

The Think Piece circulated to participants prior to the event raised the notion of dementia capable communities. The Think Tank debated the relative merits of dementia specific community development with some concluding that community development should be seen in a wider context rather than through the narrow lens of dementia. This issue requires further exploration to ascertain if people with dementia really can benefit from general community development or whether dementia specific programmes would deliver better results. Evidence should be taken from existing community development projects.

Community empowerment

The Coalition Government defines community empowerment as ‘creating communities and neighbourhoods who are in charge of their own destiny, who feel if they club together they can shape the world around them.’

In our Think Piece we suggested that for people with dementia this translates as ensuring that people living with dementia remain active agents in their community and neighbourhoods, that their contributions are valued and respected. Where people with dementia who can no longer remain as active participants in their communities remain as respected and valued members of those communities and the communities have positive regard for people living with dementia.

Andrew Chidgey provided a presentation on Alzheimer’s Society’s Community Dementia Forums. Toby Williamson from the Mental Health Foundation outlined some of the key issues in approaching user-led organisations.

To explore the issue in more depth we asked Think Tank participants to think about the following;

1. What can be put in place to enable people living with dementia to feel empowered and in charge of their own lives?

⁴ <http://humanlibrary.org/> Martin Etheridge Human Library UK National Co-ordinator 03034441340

2. Who or what organisations are in a good position to make community empowerment a reality?
3. What difference will empowerment make to the lives of people living with dementia?

The following reflects the ideas that emerged from round table discussions.

The work presented by Innovations in Dementia showed that a number of the people with dementia who participated in their research lacked confidence and had low expectations of what could be available to them in their communities.

People with dementia said that as their dementia had progressed they were worried about their ability to cope and they were concerned that people didn't understand or know about dementia. Almost without exception – people blamed dementia, rather than shortcomings in the environment or community.

Whilst the Think Tank respected the right of people with dementia to create their own definition of empowerment it was also felt that the lack of confidence and low expectations limits the potential for people with dementia, as a community of interest, to become more empowered and to take more control of their own lives.

The issue of empowerment is closely related stigma and to the relationship with professionals in care and support services. The Think Tank concluded that there is a need for some relinquishing of power by some professionals at the same time that people with dementia need to take back some of the power that is removed from them through stigmatisation and discrimination.

Social movement

The Think Tank addressed the issue of political and social status of people with dementia. The voices of people with dementia are not clearly or frequently heard at local or national level.

The Think Tank explored the parallel with social rights movements such as physical disability, working age adult mental health and HIV and AIDS movements and acknowledged there were lessons to be learned. For example, physical disability is no longer accepted as a justification for exclusion either in terms of physical access to social engagement and so too the presence of dementia should not be a reason for people being excluded. Initially there was huge stigma regarding treatment of people with HIV and AIDS but the young, vocal activists made it clear that was not acceptable and they soon gained rights to high quality services – at whatever cost. The same entitlements should be available to people with dementia.

The Think Tank debated the challenges presented by the medical and social model of disability presents. Many debates polarise the two models but it was acknowledged that both models have their place; medical models are right in terms of clinical interventions but individual pathology should not be the dominant model. Likewise, the mental health and disability movement has largely excluded dementia from activities relating to social models. Non-the-less a number of participants believed that dementia should look for coalitions in the belief that strength would be gained by developing collective empowerment. The Think Tank also explored a third

model; the community model where people with dementia are held in positive regard by and supported through their social and geographic networks.

The Think Tank suggested that one of the solutions to community empowerment would be the creation of a national network of user-led organisations that will raise the visibility and turn up the volume of the voices of people with dementia so that society and professionals are compelled to respond. In Feb 2010 Claire Goodchild Team commissioned a Think Tank on user-led organisations for people with dementia and the report is attached as annex c.

The Think Tank made a comparison with Mumsnet; there is currently no media coverage of issues relating to parenthood that does not include a reference to the position that Mumsnet takes. The ambition is that a powerful social movement of people with dementia will emerge and will be a prominent, first call reference for all things relating to dementia.

Other methods of empowerment for the community of people who have dementia include;

- Arts based activities where a person is able to express themselves through creative media. There is also the opportunity for the wider public to view and experience arts based work produced by people with dementia.
- Life story work is enormously powerful for raising the profile of individuals with dementia, particularly those with more advanced dementia for whom verbal expression might not be their primary means of communication.
- People who do not have dementia can learn how to communicate with people who do have dementia

The Think Tank addressed the challenge of identity and dementia. Whilst 2.1% of people with dementia are under 65 years of age, dementia is primarily a condition associated with ageing and thus is a victim of ageism. At the same time, people with more advanced dementia - and those who live in care homes - are absent from debates and most mechanisms of engagement (we regretfully acknowledge that the perspectives of people living in care homes and with more advanced stages of dementia were not included this Think Tank).

Public service reform

The Coalition Government's Big Society defines public service reform as removing centralised bureaucracy, giving professionals more freedom and opening up public services to new providers.

The Think Piece suggested that for people with dementia, public service reform meant enabling services to engage more effectively with community members who are living with dementia. For organisations to work in partnership with each others and to deliver the types of services and support best tailored to their needs and aspirations of people living with dementia.

The presentation from Trevor Hopkins from Local Government Innovation and Development advocated taking an assets approach to communities rather than a needs/deficit approach that is dominant in the public sector.

The Think Tank participants were asked to consider the following questions;

1. What are the advantages or challenges to public service reform as described above?
2. What kind of public service reform needs to happen to improve things for people living with dementia?
3. Who is best placed to make public service reform happen?

The Think Tank was clear that the role of public services is to ensure fairness of provision to disadvantaged communities of interest and geography. The public sector was introduced for a clear purpose and that should not be forgotten in the Big Society debate.

Yet, the Think Tank agreed the time is right to review the role of the public sector and particularly the relational dynamics between public servants and professional groups in order to rebalance personal and collective agency for action. The outcome of the review should be to unify people living with dementia and professionals and should certainly not polarise them. It was felt that many providers of support and services to people with dementia across all sectors know what needs to be done but often don't know how to get there so more support in change management is required. The value of time out for thinking, reflection and innovative planning was recognised as an important part of the solution.

Turning first to professionals, the Think Tank was reminded that dementia was probably being discussed in parallel by different groups of professionals across the country. Some participants surmised that some of those professionals simply wouldn't understand the conversations that were taking place in the Think Tank. Some participants in the Think Tank felt that dementia is too 'professionalised' or, more specifically, too medicalised. Whilst specialism is necessary to further the quality of support and services to people living with dementia, specialism needs to work within a wide context of other services and support and in harmony with people's lives. A good starting point for professionals to reform is to have at least as many conversations with people living with dementia as one has with professional colleagues.

Some participants challenged the current priorities set by the DH National Dementia Strategy programme. The initial strategy represented the breadth of issues that need addressing to enable people to live well with dementia but some participants suggested that people with dementia would not necessarily place early diagnosis as a priority. Some felt that the current programme was professionally – more specifically clinically – driven. The Think Tank suggested that the DH could work across government to drive a more rounded dementia programme.

The solutions to the imbalance of power between people living with dementia, professionals and the public sector include;

- the development of user-led organisations as described in the community empowerment section above
- a review of the cultural values of the public sector that either enable or disenable the voices of people with dementia to be heard and acted upon
- commissioners and providers across all sectors to understand the skills, knowledge and experiences that maintain and enable people living with dementia to remain strong, resilient and energetic

- an understanding of the comparative costs and outcomes of community based activity and professional services so that opportunity costs can be evaluated and resource allocation re-balanced as necessary
- service providers understanding their role in relation to a whole context of the life of the person with dementia and take a more enabling and facilitative one rather than a dominant one
- review how risk is approached and take a person-centred approach to enabling and managing risk⁵

One way to proceed is to examine who does what best and to rethink the distribution of public funding to support the full spectrum of needs that people living with dementia have. The notion of the public sector as *investors* in communities and neighbourhoods was supported by the Think Tank.

From a strength or community assets based approach this must include investing resource into *things* that are outside of the existing deficit, needs based focus of the system – investing in resources that people use to build and maintain resilience, well being and cohesion. This calls for a systemic approach to investment in communities.

The Think Tank also considered the exclusion of people with dementia from mainstream services and suggested that one of the solutions was for leaders to recognise the rights of people with dementia to access their services and to show leadership in ensuring that happens. The Think Tank suggested 3 possible routes to this solution;

- Rigorous application of the Equalities Act 2010
- Leaders accepting the responsibility to learn about the needs of people with dementia
- Empower locally elected members to ask the right questions about how local services are meeting the needs and aspirations of people with dementia.

The public sector has existing mechanisms by which this can be achieved; aligning a Joint Strategic Assets Assessment (JSAA) to the local Joint Strategic Needs Assessment (JSNA) helps investors understand more readily the useful resources needed by communities that are about place, participation etc.

Conclusion and next steps

There are interdependencies between social action, community empowerment and reform of public services. Ideally there will be a symbiotic development of the three elements of the Big Society for people with dementia.

The Think Tank was successful in exploring challenges and raising a wide of possible solutions to the problems.

This report will be widely disseminated. We offer it to policy makers, social entrepreneurs, researchers, commissioners and providers of mainstream and specialist services across all sectors and to local communities to take forward the issues and ideas that emerged from the Think Tank.

⁵ See Nothing Ventured Nothing Gained: risk assessment for people with dementia http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121492

If we were to repeat this Think Tank in a years time we would be delighted to see evidence of tangible improvement to the quality of the lives of people living with dementia.

Our thanks to all presenters and to all participants for their hard work throughout the day and for their subsequent contributions.

Report authored by:

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claire.goodchild@dh.gsi.gov.uk

with editorial input from Simon Rippon

Annex A

Think Tank Attendance list

Surname	First Name	Job Title / Company
Abley	Clare	Nurse Consultant Vulnerable Older Adults, Newcastle and North Tyneside Community Health
Ash	Christine	EDUCATE
Barradell-Smith	James	Corporate Development Manager, Alzheimer's Society
Butterworth	Olivia	DH lead for Big Society and Voluntary Sector Policy
Chidgey	Andrew	Head of Policy and Public Affairs, Alzheimer's Society
Chipchase	Helen	People & Policy Manager, BT
Dartington	Tim	Writer and social scientist
Davies	Ursula	Senior Project Manager, Design Council
Downs	Prof. Murna	Head, Bradford Dementia Group, University of Bradford
Dunlop	Peter	EDUCATE
Eley	Ruth	Department of Health, National Programme Lead (Delivery), Older People and Dementia
Etheridge	Martin	Head Of Partner Engagement - Big Society Programme Team, Department for Communities and Local Government.
Foot	Jane	Independent Policy Advisor, LGID
Fury	Peter	EDUCATE
Gage	Chris	Director, Ladder to the Moon
Goodchild	Claire	Department of Health, NDS Implementation
Hare	Philippa	Programme Manager (Policy and Research), Joseph Rowntree Foundation
Harrison	Elaine	EDUCATE
Hurst	Philip	National Development Manager, Age UK
Hurtley	Rosemary	Managing Director, Relationships Care Community (RCC) Ltd
Kaiser	Polly	Mental Health Development Unit, National Lead for Mental Health in Later Life
Keady	John	Professor of Mental Health Nursing and Older People, Manchester University
Lee	Norma	Deputy Director, Professional Practice, Bournemouth and Pool PCT
McGettrick	Grainne	Alzheimer's Society of Ireland
McShannon	Jennie	CE, Federation Irish Societies
Milton	Steve	Innovations in Dementia CIC
Morris	David	Director, Inclusion Institute (University of Lancashire & Kings fund)
O'Shea	Eamon	Irish Centre for Social Gerontology, School of Business and Economics
Rauf	Akhilak	Health & Social Care Projects Manager, Bradford Council
Rippon	Simon	Regional Dementia Strategic Lead, North West Joint Improvement Partnership
Roberts	Sue	EDUCATE
Roberts	Yvonne	Senior Associate, Young Foundation
Robertson	Guy	LGID (Ageing Society programme)
Sands	Alice	EDUCATE

Savitch	Nada	Innovations in Dementia CIC
Schneider	Kate	NHS SW and the SW Dementia Partnership
Sharp	Samantha	Alzheimer's Society, Senior Policy Officer
Sidwell	Becky	DH Project Manager, Social Care, Local Government and Care Partnerships Directorate
White	Claire	EDUCATE
Williamson	Toby	Head of Development & Later Life, Mental Health Foundation
Wright	Katherine	Communication Manager, Nuffield Bioethics

A think piece for the Dementia and the Big Society think tank

16 February 2011

Big Society is a major policy theme for the Coalition Government. The detail of Big Society is emerging as are the critiques on the opportunities and challenges that reform of the roles and responsibilities of central and local government and the relationships between the state and society.

This paper begins the discourse on dementia and the Big Society. It begins to explore the triangulation of the 3 central themes of the Big Society and particularly focuses on dementia in the community.

Context:

There are over 750,000 people with dementia in the UK and this figure will rise to over a million by 2025. The current cost to the UK economy is over £20 billion per year including an £8.2 billion to the NHS and social care.

The Department of Health in England published *Living well with dementia: a National Dementia Strategy* in Feb 2009 (1). The Strategy primarily focuses on improving health and care services and has prioritised the provision of health and care services - early diagnosis and intervention, hospital care, care homes and reduction in prescribing anti-psychotic drugs – in the Strategy implementation programme. The DH Strategy has also included some wider issues such as raising public and professional awareness through a national media campaign.

Whilst the main thrust of activity has been focused on improving health and care services, the Coalition Government's Big Society provides a platform on which to consider wider issues of living with dementia. For reasons of demographics, cost and citizen rights it is timely for society, policy makers and service providers to think about enabling people to remain in their social networks for as long as possible.

There are 3 key themes of the Coalition Government's Big Society agenda:

- Social action - fostering and supporting a new culture of voluntarism, philanthropy and social action.
- Community empowerment - creating communities and neighbourhoods who are in charge of their own destiny, who feel if they club together they can shape the world around them.
- Public service reform - removing centralised bureaucracy, giving professionals more freedom and opening up public services to new providers.

In relation to dementia these three themes might translate to:

Social action: harnessing the power of social action to support and enable people with dementia to remain in their own homes and their own neighbourhoods and social networks for as long as possible. This would require the general public having a greater understanding of dementia and how they might support people to remain as active members of those neighbourhoods and communities. And how, through social action such as volunteering, people living with dementia can be best supported in social networks and in using community resources.

Community empowerment: ensuring that people living with dementia remain active agents in their community and neighbourhoods, that their contributions are valued and respected. Where people with dementia who can no longer remain as active participants in their communities

remain as respected and valued members of those communities and the communities have positive regard for people living with dementia.

To enable this to happen

Public service reform: enabling public services to engage more effectively with community members who are living with dementia For organisations to work in partnership with each other and with people living with dementia to deliver the types of services and support best tailored to their needs.

The motivation and incentives for organisations, neighbourhoods and individuals to engage with dementia are varied. For example;

- Individuals who have personal experience might be motivated by the desire to see improvements in the quality of life and respect of people with dementia and, where they have received good quality support, might want to 'give something back'
- Business sectors might see commercial advantages in providing good quality services to people with dementia or they might want to discharge their social compact by supporting projects related to dementia
- Neighbourhoods might recognise that they have people living with dementia amongst them and want to be more inclusive of all community members

Because different motivations manifest in different endeavours and result in different gains there is a need to develop a large framework for what the Big Society means for dementia. At the Think Tank we aim to begin creating that wide framework. We suggest that an assets perspective is a useful way of approaching the subject.

An assets based approach

An assets approach values the strengths, capacities, skills, knowledge and connections within individuals and communities and seeks to maximise these assets. Traditional approaches focus on deficits, problems and needs with responses from services to provide more and more provision to 'fix the problem'. This leads to dependence on outside support and a negative story of place and identity. An asset approach builds community solutions in a more sustainable way and more efficient use of outside resources. Such an approach also takes a systemic view of the person and place in terms of assets, solutions and resources.

Two thirds of people with dementia live in their own homes in the community. The remaining third live in long term care settings - also within neighbourhoods and communities. For those living in their own homes and for some of those living in care homes participation in normal community activity is vital for their well-being. It is therefore logical that assets are applied to communities to develop *dementia capable communities* to create places that are "friendly", "safe" and "enabling" for people with dementia. This approach has potentially great utility for the sectors of health, wellbeing and social care support; the paradigm has a strengths based view of people and place as opposed to a deficits or needs based view, has at its heart a focus on place based partnerships and power sharing across sectors, with people⁴. We are currently developing a dementia community assets models which planners and people living with dementia can better understand the component features for Dementia Capable Communities illustrated across 3 levels - dementia aware, friendly and capable^{*c}.

The National Dementia Strategy says of the needs of people with dementia that at particular touch points people living with dementia require the support of specialist services but acknowledges that for much of the time "some people will just want access to services that should be available to everyone locally, such as transport, leisure, housing and information" (p47). The challenge for the community – and service providers - is to understand how they can support a person's continued engagement as active participants and to support those who can no

longer actively engage and the challenge for specialist services is how they can support the community to be more knowledgeable and inclusive.

An assets approach aligns with the Big Society agenda in the following way;

- i) Developing social action: that illustrates an ethos of people forming and using networks, volunteers, community support circles that support people to live well with dementia and that impact on the issues of stigma and discrimination.
- ii) Building Community Empowerment: That mechanisms are set out wherein local people can readily engage with local service planners, providers to best shape and inform outcomes and benefits – a co produced agenda.
- iii) Public Service Reform: Through local engagement, people more readily shaping the type of services and community assets that need investment. This will see triangulation with commissioners/investor, providers and local people who may use such resources directly or have a vested interest in how resources are utilised.

As the momentum grows in these 3 areas; where people are increasingly living well with dementia, key strategic outcomes would be realised that illustrate greater individual and collective involvement in local communities, better processes for engagement and co production in place shaping and increased investment in social and community networks that build cohesion.

We acknowledge that such a shift will require a radically different mindset in some public and private sectors and a move toward investing differently which will be a challenge in the current financial climate.

We accept that the current economic climate for local systems is difficult but we would encourage a discussion and review as to how the points highlighted in this paper can be seen as part of a new system response to these difficulties.

References:

1. Department of Health 2009: Living Well with Dementia – a national strategy for England.
2. Building the Big Society: Cabinet Office May 2010.
3. The National Dementia Declaration: Dementia Action Alliance October 2010
4. A glass half full: How an asset approach can improve community health and wellbeing: IDeA (part of the LGA group) March 2010
5. Mental Capital and Wellbeing – Foresight Group - Scientific Review B3 2008.
6. Mental Capital and Wellbeing: Foresight Group 2009

Note

* a. McKnight J et al use this word to mean resources which are available to and used by people and seen as assets.

* b Living well with dementia – We use this term to account for the person with the diagnosis of a dementia and those people associated with that person, friends, family members etc often involved in the persons life and networks.

*c Dementia Capable Communities – A Framework for Action and Understanding. – Simon Rippon & Claire Goodchild at www.dementiacapablecommunities.org in 2011.

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Developing a model of engagement for people with dementia – report from Think Tank Feb 2010

1. Engagement with people with dementia – background

A one day ‘thinktank’ was held on 24th February 2010, in London. The purpose was to bring together key people to discuss what the Department of Health could do to support the development of a model of engagement for people with dementia. Innovations in Dementia, a community interest company that carries out user involvement work with people with dementia, were asked to organise and facilitate the day.

2. What is the purpose of engaging people with dementia in developing policy and services?

- To put people with dementia in control of their lives as individual citizens and to promote the wider involvement of all people with dementia in service development and delivery.
- To ensure that public resources are used most effectively aligned to meet the needs of people with dementia, their carers and families.
- To make sure that services recognise the specific and changing needs of people with dementia.
- To develop evidence about what is most effective in supporting people with dementia, their carers and families to live their lives with dementia.

2.1. Programme: Short trigger presentations were given to encourage people to think about the type of models that might have some relevance for ongoing engagement with people with dementia:

- *Edward McLaughlin* from the *Scottish Dementia Working group* talked about a user led campaigning model, run by and for people with dementia, with a paid person to support the group’s activities. The group has 85 members, with approximately 5 very active members who make public presentations. The group have influenced a range of organisations including the Scottish Mental Health Collaborative and the Scottish government.
- *Lynne Elwell* from Partners in Policy Making described the training courses they run to equip adults with disabilities and parents of children with disabilities to understand and navigate their way through the health and social care systems. To build capacity, graduates of the courses then train other individuals and families.
- *Tony Bennett* from *Carben Consultancy and Training* described the *Citizen Leaders* programme. Tony attended a Citizen Leader’s Academy to gain knowledge and skills to speak up as a carer about

self-directed support and individual budgets. There are currently about 20-30 active citizen leaders across the country

Presentations were followed by small table and large group discussions to explore what a good engagement model for people with dementia might look like, including how it would work and the support that would be needed. Suggestions were put forward for the design of possible models that would support the engagement of people with dementia in health and social care.

- 2.2. Participants:** All invited participants had an explicit interest and perspective on engagement work with people with dementia. 20 people participated in the day, including people with dementia and carers, and representatives from The Department of Health (national and regional leads), For Dementia, Alzheimer's Society, NHS Confederation, Dementia Advocacy Network, London Borough of Camden, Mental Health Foundation, Bradford Dementia Group, Innovations in Dementia CIC. Rachael Litherland from Innovations in Dementia facilitated the day.

3. General principles of a model of engagement

There was a lot of consensus at the meeting about the purpose and desired outcomes for what any engagement model should look like.

The conclusions were that any model of engagement should be:

- *User led* - driven by and centred on people with dementia
- *Flexible* - able to support the engagement of people with dementia in the things that are important to them but also to act as a collective voice of people with dementia
- *Representative* – of all people with dementia, including those with more advanced dementia. This needs to recognise the importance of carers and advocates, particularly for people in the later stages.
- *Willing to make the most of* existing resources and networks, rather than starting from scratch. This might include other engagement models, as well as families and advocates
- *Able to equip* people with the necessary skills and confidence to participate and engage – this includes people with dementia but also those that would support people to be engaged and involved