



National Dementia Strategy.

Report of consultation with people with learning disabilities in the North East
August 2008

What we think about the Government's Plan



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Introduction

This report is provided to the Care Services Improvement Partnership by Skills for People.

The National Dementia Strategy indicates that people with a learning disability including Downs Syndrome are more likely to be affected by dementia.

The Care Services Improvement Partnership commissioned Skills for People to consult with local people with learning disabilities about the proposals. Skills for People is a user led organisation for people with learning disabilities in Newcastle upon Tyne.

Three events were held in the North East region during August 2008. These events were held in Newcastle upon Tyne, North Tyneside and Middlesbrough. An event was scheduled for South Tyneside but unfortunately had to be cancelled due to the low number of people saying they wanted to take part.

76 people came along to these events, of whom 55 have learning disabilities. 21 women with learning disabilities and 34 men with learning disabilities attended the events. 21 professionals working to support people with dementia attended the events.

At each session people were asked their views about the same questions. This report gives the comments of those who attended as recorded on the day.

Those who participated in this consultation were happy to give their views and ideas. Most had experience of knowing someone with dementia in their lives and they all have direct experience of health and social care services. Many feel strongly that the government should listen to what they are saying and would actively want to meet and talk to ministers from central Government that are leading this Plan.

Our sincere thanks and gratitude to all those who took part for sharing their valuable knowledge and experiences.

Raising awareness



1. Awareness raising

How should we make sure that many people know about the issues people face when they have dementia?

- Could have a TV campaign, advertising in the papers, radio
- Get information in Saga book (magazine)
- Tell people how to recognise the signs
- Tell people about what dementia is
- And how to recognise how people are changing
- Start in schools – disability and dementia – everyday living – make it part of national curriculum
- Characters in soaps that have dementia
- High profile people with dementia talking about it
- Trained staff to visit Learning Disability User Forums, Learning Disability Partnership Board meetings and older people's forums
- Website information linked to high profile sites e.g. DOH, NHS, National Charities
- Yellow pages, advertising, newspapers, posters on the buses, metro etc
- Have a college course on dementia
- People with learning disabilities should be trained to be dementia champions – do a campaign about it
- Write to government about ideas
- Talk to people like social workers – they give us leaflets
- Through friends – they may know someone who has it
- Training and funding for voluntary organisations e.g. advocates
- Much greater public awareness – start in schools
- Doctors to explain better
- Information on DVD – talking for those who don't read
- Use of multi media – e.g. dramas, soaps, including famous people with dementia who talk openly about their experiences such as Terry Pratchett

Summary

People said that there should be a national campaign delivered in many media forms, (films, soaps, radio), supported by a “patron” with Dementia such as Terry Pratchett, and by champions with

learning disabilities. Awareness raising should be provided by people who have dementia early on in schools to raise awareness and reduce stigma. Good accessible information should be provided in many forms.

Providing a well trained workforce



2. Providing a well trained workforce

How do we get well trained people who provide a good quality service?

- Training produced by people with dementia in schools, on social work courses, training as doctors
- They need to know the difference between learning disability and dementia
- Courses about dementia
- Go into hospitals and train staff
- Skills for People could train people the difference between learning disabilities and dementia
- Recommended by professionals
- Police checked people
- Training for workers in consultation with those they work with and their needs
- Person with dementia and carers or family to regularly give feedback on quality of service
- Quality Checks to make sure people are getting good support
- Being sensitive to the needs of the individual
- Training to try to find out what's important – how to talk to families – PCP toolbox skills
- Training the government and royal family
- They should do courses about people losing their memory and what can help make sure they get the training
- They should know where to send you next – who are the experts
- They can guide you to the right places to get support
- All doctors, nurses, etc should get some training
- There should be courses – degrees where you can learn just about dementia
- They should get support groups to learn about dementia for family and friends
- Get professionals to understand more, know more about it and explain to patient's family and hospital
- An Occupational therapist said many professionals who work with people with learning disabilities get no training relating to dementia and learning disability unless personally interested – nothing given in depth was part of university training

Summary

A national accredited training programme should be developed by people with learning disabilities and dementia. It should also be taught as part of professional training (degree etc) to nurses, social workers and doctors. It should be delivered by people with learning disabilities, and people with dementia. This training should include differences between a learning disability and dementia and include training about Person Centred Planning tools. Quality standards should be produced to check that people are getting a good consistent service.

Getting good quality diagnosis



3. Getting good quality early diagnosis

Should there be one service?

- Yes, doctor to give advice on symptoms, and signpost to additional services
- No, confusing – possible wrong information
- Yes, information all in one place
- No, GP or specialist diagnoses, then get information and support from specialist, encouraged from the beginning to help or get good network behind you.
- People should have Advocates.
- GP should diagnose and tell you – they know better
- Specialists should make sure GP is going their job
- GP refer to specialist to make sure you have dementia – get good advice and support
- Support staff to be trained to support people diagnosed with dementia so that the individual doesn't have to leave their home
- Go back in time – conversations, themed rooms
- Reading newspapers to remember we are living in 2008
- Place you can go that is not a surgery or hospital, so that people are more likely to go to the centre and get a diagnosis
- Self checking at regular intervals – first stage memory alertness – should be part of regular health checks
- People with learning disabilities who are at risk of developing dementia should be offered regular checks of their skills, abilities, say in their 30s, which will help to make sure any changes in the future, due to dementia are not mistaken for part of a learning disability

Summary

Overall people feel that there should be a specialist service where they get diagnosed. Some feel that GP's should or could initially diagnose but should be able to pass you onto other specialist services. These services should not be in a surgery or a hospital. Advocacy should be provided to support people.

Good quality information



4. Good quality information

How can we make sure that people get good information?

- People should know what is happening – like when people have heart attacks. You know what the signs are, so you know when to get help.
- Leaflets, doctors and nurses, chemists, talking to others who have dementia, national forums, website, TV advertising, radio, social workers, key workers, support workers better trained.
- Getting information from advocates in colleges, letters, talking to other people from centres.
- Library for information, CAB – Citizens Advice Bureau, church groups, Salvation Army, charity shops – dementia with leaflets and information, identity bracelets – with name and information on, buddy travel service, young people can get dementia – lessons in schools.
- Clarity of information about drugs without the politics
- Dementia health line
- Community Health Clinics – supermarkets
- Advertising campaigns
- Going to people
- Bullet points – not big, long paragraphs
- On the news – explaining to people how important it is
- Advertise it on TV
- Information about what it's all about
- Raise money – make a booklet for Tyne and Wear
- Information on the Metro and buses – in the Metro paper
- Word of mouth – telling people – dementia campaign
- Public information points – talking walls
- Sign language classes / Braille
- In local schools – National curriculum – start early so people are not worried or frightened later on
- Radio – talk show – people ring in – main stations
- Libraries – local community space
- Life centre – exhibition
- Books – information, pictures, books, children's books about dementia

Summary

People want good quality consistent information available in many forms provide for all age groups, this includes the development of characters in children's books who have lost their memory, thorough to exhibitions, good advertising radio public transport, help lines and leaflets available in many public places.

Good support and advice



5. Good support and advice

Would you want a specialist memory service and a memory adviser?

- Yes, a memory service in each local area would be a good thing, so people don't have far to travel and it's easy to go back if you need to (18/9 people in group said 'yes').
- Different views in the group – some people thought they would like the doctor to do it (2) and other people thought it better to have a walk-in centre.
- Good to have memory service (x2)
- Both self referral and GP referral should be OK

Summary

A walk in memory service would be good in each local area, and should be easy to get to, people want to be able to go to the GP to get referred or self refer.

How could memory advisor make sure lots of people know what is happening?

- Dementia care advisor would be good – advise people about dementia, counselling, testing, support / services available, holidays, medication, benefits, etc.
- One person that advises you, and tells you about services, advocacy
- Have a key worker
- Be taken out and about
- Social services
- Taxi service to transport to and from places
- Prefer GP to refer
- Write a plan
- Meeting with friends and relatives (circle of support)
- Get staff to help you have a meeting
- Make a DVD of what you like in case you forget
- Books, information, leaflets

- Have programmes on TV about dementia
- Have tapes, CDs, radio information about dementia
- Visits to Memory Centre before getting dementia (open days, drop-in, coffee groups)
- Medication
- Memory Advisor – good also to give information to family

Summary

A Memory Advisor would be good. They could give people lots of information about the different types of help available. They could also help provide support and information to families and help with the development of support groups, information sharing etc.

Better care in general hospitals



6. Better care in general hospitals

How can we get better care in Hospitals?

- Senior person to lead and work with you
- Independent people – but who would they be?
- In the hospital my Dad went to Tonna Hospital in Neath, there was one assessment unit, then four other units that they could go to – it was good – there was a support group in the hospital
- Train nurses how to treat people with dementia
- Specialist ward for people with dementia and access to highly trained staff
- Smaller unit so people can't get lost
- 24 hour access to staff for reassurance and comfort
- Themed rooms
- Having things that make them happy / sad in plan
- Should be person centred
- Training on how to talk to people
- Someone who knows you well should ensure the person is getting person centred support
- Start this process from school awards – so its not lost – and young people do something for their future
- Find out about Person Centred Planning
- Involve carers
- Good planning for when people leave
- Nurse should care for them 24 hours – they could help them with dressing, medication, choosing meals and eating meals
- Doctors need to talk to people, remind people, give people information as many times as they need
- Talk about planning to move out of hospital to their home, and the support and services they will need
- Information about services and support can be shared with people – it is important to have information in ways people understand
- People need to be safe in hospital and not wandering off site and getting lost.
- Having memory key pads on each ward would keep people safe
- A specialist team in every hospital

Summary

There should be a specialist team with a senior lead and well trained nurses. The units should be small and designed in a way that can assist people who lose their memory i.e. themed rooms etc. Nurses should use any tools/information that the person may have developed prior to admission to assist them to continue to work in person centred way. Information should be accessible and there should be good planning involving community services when someone is leaving hospital.

Better care in care homes



7. Better care in care homes

- **What does good care mean?**
- Someone who wants to be there to support you
- Knowing what is important to me in my life
- Keeping important stories alive and passing on information so it doesn't fade away
- Good care in a care home means having it look like a 'home' – recreating past environments e.g. noises, designs, toys, etc.
- Knowing what can keep people safe
- Staff need to know what it is
- Need to talk to families more, to make sure person is looked after the best way they can
- Taking care of the person in the way they need –changing language to suit them
- I used to go into Scope homes and talk to the residents, and find out about their care. I would stay a couple of nights and go every couple of months
- Still be able to go out into community and do activities e.g. cinema and pubs, etc
- Regular visits from family and friends
- Stay in same room / home as husband or wife
- Keep and have access to your own stuff
- Look around before and have choice
- Good staff – friendly – understand health problems, good listener, understanding patient
- More staff
- A small number of people in the house
- Clean
- Good owners in charge
- Bedrooms have to look nice – television in bedroom, go to bed when I want
- Want to know the rules – what time you have to be in, what time do you have to go to bed, can you go out when you want to, can I go out by myself
- Would like to go and visit
- Want everyone to be treated fair and with respect
- Wouldn't tell you what to do
- Accessible bathroom – checked before you go in

- Be able to go out and try to keep what's left of your memory active
- Allowed to have a phone
- Want my girlfriend to be able to come and see me
- Bedroom should be private
- Should be allowed to have visitors
- Should be allowed to get take away food
- Would have to have lifts
- Someone to look after my money if I couldn't
- Someone to go to the doctors with me

Summary

The care homes should be small, designed to accommodate people with dementia. Events and activities should recreate past environments, and stimulate people. People should get support to stay independent, keep connected to their friends, families, partners and community so that they retain their identity as much as possible. People should be given a choice of homes. Staff should be well trained in working with people, be able to spend time listening, being patient and interpreting what people are saying. People should be treated with respect. The quality of care should be checked regularly by mystery shoppers who go and stay over, see how people are treated and talk to residents about their care.

Better care at home



8. Better care at home

What does good care at home mean?

- Pictures of family around home
- Flexible hours offered by support workers
- Support plans
- Choice, rights respected
- Support workers who listen / reassure
- Being given the right medication
- Carers having the right information – my likes and dislikes, what I am allergic to, a pen picture of me, a list of tasks with which I want help and how
- Carer contactable by phone 24 hours a day if not available
- Making sure your support worker has all your information
- Telecare equipment
- Support networks
- Look at ways people can still do the things they like doing
- Stephen's mum passed her driving test so that she could take his dad out.
- Continuing the lifestyle they had – finding ways to do this
- Sit in their car – pay someone to take them to places they love

Summary

People want their home to be a homely environment. They want carers who can be contacted 24 hours a day if needed, who know about their needs, wishes, and about their life and personality, interests etc. They want contact with family and informal support networks to be maintained and nurtured. They want help to continue with the things they have enjoyed in life as far as possible.

Good respite



9. Good respite

What makes a good short break?

- Some work done about where they are going – get to know staff and place before going.
- There should be a person centred approach to planning short breaks.
- Person with dementia to be involved in choosing and planning the holiday.
- More family awareness of dementia so the family can understand how to support someone – not just the immediate family
- Own belongings taken with the person on short break.
- Give person with dementia a picture to remind them of the break / holiday and family and workers to use pictures to remind.
- What about foster carers for people with dementia for respite.
- Support workers know where you want to go and assess lots of choice
- Bringing holiday information to help you choose your destination
- Someone going through your Person Centred Plan with you
- Help you use the internet
- You should get help to save through the year, so you can pay for a holiday
- Companion to travel with
- A key worker could travel free
- Better transport links
- More choice, easy accessible information
- Arrange short breaks in conjunction with friends
- Better communication between travel agent, client, support worker and hotels

Summary

The person should be involved in choosing their holiday as much as possible. If this is not possible then those deciding about a holiday should take into account the kinds of holidays the person has enjoyed before. If a person is going to a care home then they should be well prepared and be able to visit beforehand and have as much choice as possible. When they go they should be able to

take personal items that can remind them of home, and photos of family and friends to help them communicate with people.

More control over care



10. More control over your care

What would give you more control over your care?

- You should have your own money
- Trained staff to help
- Involving family and good friends
- Write in your plan what to do in an emergency
- Have help to stay in your own home and family surroundings
- Person centred planning for people with dementia
- Loss and bereavement courses for death and loss
- Carers talking about how dementia has affected them
- Awareness raising – have fundraising events to raise awareness
- Reminiscence sessions
- Keep a memory box
- A night time service where people can go overnight or get support to give carers a rest
- Who could help me because I live on my own?
- I would want to get into a routine
- I would need support to go on public transport
- Special centre to go to
- I would need someone with me so I could keep doing the things I wanted to do
- Getting money (pension) out of the Post Office - might need help – might forget they've got it
- Would want my support worker to be able to do more
- Special help like the team which helps when people behave in ways staff find difficult

Summary

People can have more control in their lives, and over their care through good planning involving family and friends about how to stay independent, and through making sure that carers know about the plans. There should be a plan in place about what will happen in emergencies. Memory boxes which contain things that are important to people in their lives are useful.

People told us things which would help them stay in control of their lives: good support to stay in their own homes, good local groups like reminiscence groups, carers groups, and education about loss and bereavement.

Improving local services, ensuring that disadvantaged people's needs are met



11. Will this plan improve local services, and ensure that disadvantaged people's needs are met, for example people from black and minority communities, and people with learning disabilities?

- One to one activities support workers, need to be high on the priority list
- Commissioners should set standards – a lifestyle package, using stories with messages to follow these principles. The standards would provide a check list – have you looked at their interests, have you consulted the family and friends?
- Early, well planned support can end up being much cheaper: support 2 nights a week – rather than emergency support later
- People with learning disabilities and people from black and minority communities often receive a lower standard of care so for those with dementia could have even lower support
- Certain behaviours / habits may not be supported, but put down to dementia and causing much distress
- Familiar places / activities are a comfort – even if this cannot be expressed
- Independent person centred teams needed – through charities, volunteer organisations, not tied up with money, attached to residential home or area – well funded, not just relying on volunteers, well paid staff and use personal experience
- Training people with learning disabilities and people from BME communities to train, support, give information and advice to others

Summary

Commissioners should set standards providing a check list of what is expected of those who support people with dementia (“lifestyle package”). This can be used to ensure support is given in a person centred way, and people are supported to stay as independent as possible.

Professionals should be trained to distinguish between behaviour that is related to a person's learning disability or their preferred communication; and that of dementia.

Good training for staff. Independent person centred planning teams in the voluntary sector should be commissioned.

12. Things that have been missed

Government need training. We need to speak to them as well (through Skills for People).

What if my family placement carer is not well? Person Centred Plans should plan for future – to say what if a carer becomes unwell. Think about dual support.

Making sure that questions at assessment are accurate i.e. some people with learning disabilities may not know Prime Minister, date of birth, etc.

Teaching children in schools at an early age- as part of the national curriculum.

Information on TV, DVD, Braille etc.

Summary

Good assessment is to enable professionals to distinguish between a person having a learning disability, or dementia.

Those involved in person centred planning should help people to plan for their carers being unwell.

13. What should be done first?

- We need to talk to government first and find out what they think. We should train them.
- How people are going to be supported to live in their own homes.
- Awareness difference between dementia and learning disability one of the first steps.
- Role plays
- Keep structure for people with learning disability who live in independent supported living.
- Consider housing plans before person moves into supported living. Make sure their home is suitable for them.
- Skills for People should train the government. Get the government to our meetings. Get Gordon Brown or minister that is leading it to care to meeting or forum. Get nurses to look at government plan.
- Good information
- Listen to what we say

Summary

We need to talk to the Government and train them about the difference between learning disability and dementia. They should hear what we say and act upon it. This awareness also needs to be transferred to other professionals. Good quality information should be made available about the plan and how it is progressing. There needs to be some work about housing and people with dementia.

14. Timescales

What should the timescale be?

20 years

10 years

5 years

4 years

3 years

2 years

1 year

Summary

People found this a difficult question to answer. People said that the plan should happen as soon as possible

15. Conclusion

The people who participated in this consultation had a wealth of knowledge and experience to contribute. Most of the people had experience of knowing someone who had dementia in their lives and they have direct experience of health and social care services.

Many of the people who participated feel strongly that the government should listen to what they are saying and would actively want to meet and talk to ministers from central Government that are leading this Plan. As the Strategy progresses and develops it is crucial that people with learning disabilities continue to be consulted at every level, so that the plan truly reflects their views wishes and needs.

Skills for People would be very interested in continuing to support the inclusion of people with learning disabilities in the developing Strategy at both Local and national level.

The main findings of this consultation are as follows.

Working alongside the Government

- People with learning disabilities really appreciated being involved in the consultation and would like to be actively involved in the progression of the Strategy

Awareness raising

- National Campaign and awareness raising events, radio TV characters in soaps to reduce stigma
- Awareness raising and training for school children.
- The development of resources in the community that provide information support and guidance such as memory maintenance, and loss and bereavement courses.

Training for professionals

- National accredited Vocational and non vocational training. Training for nurses, doctors and social workers, with specialised degree courses.

- Specialist small units for people in hospital with themed rooms and sensory stimulation that remind them of the past
- Well trained support staff to support people in their own homes and in care homes, these staff should be trained to listen, interpret and retain people's independence and skills as much as possible.

Diagnosis

- Good early Diagnosis so that people can access a variety of services and support to remain independent.
- The development of new assessment materials which clearly define the differences between having a learning disability, and dementia
- People with Learning disabilities who are at risk of developing dementia should be offered regular checks of their skills and abilities, which will help to make sure that any changes in the future, due to dementia are not mistaken for part of a learning disability.

Information

- The development of good quality accessible information made available in a variety of mediums i.e. radio TV etc.

Good Support and advice

- A walk in Memory service in each local area, easy to get to.

Hospitals

- The development of specialist teams in hospitals, with senior leads and well trained staff
- Good planning when people are leaving hospital

Being person centred

- Person centred planning tools implemented across all services from early diagnosis through to end of life to create a seamless service for people

- Early planning with people when they have the capacity about their future values wishes and beliefs should they get dementia
- Commissioned independent person centred planning teams from the voluntary sector

Care home design

- Small Care homes designed by people who have experience of dementia. With events and activities recreating past environments that stimulate people.

Respite

- Person centred respite services and people involved in planning their holiday

Care at home

- Good support to stay living in their own home and retaining independence

Quality services

- Quality standards for all services

16. Evaluation

This is what people said about the sessions

- Hopefully the government will listen
- You have got lots of information from us
- I enjoyed it
- I loved it
- I enjoyed the questions
- Trying to get answers across
- I thought it was going to be hard, but it wasn't
- It's good that the government has a plan for dementia
- Good that I think the Prime Minister is going to sort this out
- It was good to learn and listen about dementia and speaking up about what we think and listening to others views (in the small and big groups)
- I remember about Alzheimer's and what it is
- The presentation and food were good
- I learned more today that I would at any professional presentation" – member of professional carers organisation
- Good
- It was easy to understand
- We gave lots of information
- Not enough time to do it – would have liked to spend longer – you can get into this type of topic
- Fantastic
- Fabulous
- Very good
- Great
- Nothing bad to say about this afternoon
- There should have more information about dementia – there was a lot of information, but should have been more
- We got to air our views
- Will they actually do anything about the data collected?
- Things need to change very soon for people with dementia as support / care is so much less than those with other diseases / illnesses

- I learned a lot from a family member of someone with dementia. This family appear to have good support with possibly is due to fathers profession, vicar and his mothers intervention
- I found the information about the dementia strategy most helpful
- I liked being able to express an opinion that will go back to the government
- I will take away how much I learned from someone who lives with someone who has dementia and the progress of the illness
- It was good working in a small group, because it enabled every voice to be heard
- I found the information about dementia most helpful
- I will take away with me that it's going to cost a lot of money to look after people with dementia

17. Our stories and experiences

I call him a stupid man – but he's not. It's hard because me and Anthony have problems, especially when I need advice. He is nicer now than when we were young, because he no longer hurts me.

The doctor thought I had dementia, as I was messing my words up. He took blood, but no one told me what the reason was.

My dad lives in hospital. When my husband walked in, dad said "Look at the old devil, he's my son in law" – he does remember some things.

My neighbour went to South Shields to look for her mum – the police found her 2 days later and brought her home.

My dad was a very placid person – now he's very irritable.

They may get behind in their learning.

People need to be aware of it – the more you know, the quicker you get help.

We talked about taking tablets – but what happens if you forget to take your tablets? My friend's boyfriend does everything for her – he needs more help than he gets – she gets taken to places – it's the same people supporting her each time.

People go to hospital – like Northgate because they know about dementia.

My dad went to hospital that specialises in dementia – there are 4 units, assessment, they were going to put him in a nursing home, but he died before they could.

On hospitals: Not enough staff to help you. Don't got a test for dementia because hospitals are worries they will have to look after them for longer – people don't know where to go – people get moved about from ward to ward – if you have dementia with all above, it makes it harder.

“It’s about time somebody did something”

“Does the NHS diagnose or test for dementia?” – It varies, some do, some don’t – it’s not all good – some doctors are worried about diagnosing. You need the label to get the support.

The psychologists came to the house to do a test on my dad. She asked him questions like who is Prime Minister. What day of the week is it?

My dad clocked onto the doctor asking the date – he would rip the date of the paper to remind himself.

We might not always know the answer to the question – se we might fail the test, but it’s not that we have dementia – it’s our learning disability e.g. I don’t know the time.

They need to think about the tests so that mere people with learning disabilities are not wrongly diagnosed.

Find out early and get in touch with a support group.

May mum is physically unwell, but dad has dementia and if she takes bad what happen? Social worker talked of holidays not respite. Need to train social workers to be social workers – daft.

“Why don’t they say ‘short term care’, not ‘intermediate care’?”

When I worked at Scope I used to visit residential homes and check quality staff. I used to go and sit amongst the residents, staff would forget I was a member of staff – I used to report to the boss when I was there, they didn’t realise they were being checked. Someone had to wait 20 minutes to go to the toilet.

I once stayed overnight at a flat and went the bathroom, it took 2 hours to find a staff member to get the keys, and they knew I was coming.

Staff don’t know how to support – staff say “No, that’s wrong” to statements people make about their ‘realities’ – staff stress people out – it easier to be nice, than going off it.

Go back to the time they remember – pictures etc.

At the hospital my dad was at there were lots of old gathered things e.g. flat irons, old clock on mantelpiece – he used to talk about it and remember.

Do stuff that takes people back – it would be so easy to do it good – not to abuse people – cannot protect people from it – I'd hate to think someone was getting / having a bad time

Friends as supporters – I can go with my friend to more places than I could without support. Winnie said I was taking too many tablets – you've got to get off them – I no longer take them – I'm much better now than I was when I was taking them.

I think people who have got any disability, unless you know someone who knows about disability before getting to know you it's hard. You cannot put people with other who have dementia, because it's hard – you get irate. There is nobody more patient than my dad, and I irritate him.

Being person centred – taking what's important to the person and letting other know e.g. TV or radio, shave or no shave, shower or bath?

In my family 5 people have had dementia – could it be coincidence or genetic?

You can take tablets that prolong it, but you still die from it – it gets worse, your body starts to close down – stopping eating, losing weight, then dying etc.

Definition: People who lose their memory don't know what they are saying all the time.

- My friends died when she was 30 or 40
- Alzheimer's – it's when they go back to a time they remember
- If they've got a husband they won't remember them
- My dad dies of MRSA
- Will I get dementia? (said in relation to LD and risk)
- Have they got proof people with learning disabilities are at risk?

- Sometimes people can get angry because they don't understand them and they may pass out
- They repeat themselves
- Families are embarrassed of the individual – they think they are going mad – but they are not
- Can affect one family – don't understand how or why people forget things
- Senile dementia – it's the wrong word – it puts people down, there should be nurses and carers who can look after people in their homes or good centres
- There's no centres for people with learning disabilities – there used to be stacks – now there is none
- Can you ask the doctor to get on E.G. to see if your memory is still there?
- In order to have 1 place for assessment, you have to know what the difference is between learning disabilities and dementia – I don't know who the queen is, but it doesn't mean I've got dementia
- Commissioning – why don't they just say buying the services
- I don't believe in a care home – I don't want to go – better nurses and managers will make care homes better
- Staff at hospital I was in didn't ask what tablets patients want to be on, they could be anything
- The way staff talk to people can be bad and make the person angry – have themed rooms to suit people's needs
- I heard someone shout at a neighbour who was Alzheimer's "Don't be silly, your mum is dead"

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