

DEMENTIA QUESTION AND ANSWERS

**This information has been produced following
a question and answer session**

at the

North Sedgemoor Health Forum

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This information is a guide only, please consult your GP if you have any symptoms or need advice on medication you are taking.

DIAGNOSIS

In diagnosis how is one form of dementia differentiated from others?

Dementia is an umbrella term and the different types of dementia come under this, such as Alzheimers, vascular dementia (which affects how well the oxygen supply gets to the brain through the blood supply), mixed picture (which is some vascular change and Alzheimers together), lewy body (which might cause patients to experience hallucinations, difficulties with visual perception, falls and intense fluctuation of symptoms).

A clinician would look at the history of the patient and listen to what they are saying has changed, which is crucial. They look at their pre-morbid skills and how a patient functioned. This is followed by a neuro-psychological assessment where various tests are carried out looking at memory, language, executive functioning, visuospatial skills and concentration. Dementias have different clinical profiles so test results, brain scans and patient history is looked at as a whole before diagnosis is made.

In vascular dementia there may be a more patchy profile depending on which area of the brain is affected by the lack of oxygen. When oxygen is cut off to brain cells they don't get fed and subsequently die, so people who have strokes or brain clots may have problems with speech or their limb function as those areas of the brain are not getting oxygen. People in the early stages of Alzheimers typically have problems with word finding and short-term memory loss, if it moves to the frontal lobes this will give a behavioural variant – a change of personality or saying/doing inappropriate things. A posterior cortical atrophy is where patients have deficits with their visuospatial skills.

If people are worried about their memory they need to see their GP in the first instance to get signposted to the right service (i.e. a memory clinic).

Would dedicated scanners help in diagnosis of dementias and which type would be of most use?

Everyone is offered a CT scan but this does not make the diagnosis. Scanning people is carried out to exclude other diagnosis, for example have they got a brain tumour have they had a massive stroke or head injury, which need to be excluded clinically.

A CT scan is just part of the puzzle along with the clinical diagnosis. The clinician will also listen to the patient and their relatives. Scans are useful and are better for rarer types of dementia. An MRI scan is more sensitive to detecting brain changes.

Can you tell us of any improvement in the methods of diagnosis since the move to the Mulberry Centre?

There is as very close knit team in the Mulberry Centre, there have been some staff changes and new people joining the team with different skills. The service is always updating the way they work and the forms they use. Dementia sufferers need to be asked helpful questions to find out what they know instead of being drilled with the same questions so they remember the answers, as this will not help with an accurate assessment. Hospitals and GPs are being given training by the service and have been asked not to use the Alzheimers dementia memory test more than once a year. It is important to find out how well the brain can cope with these questions not how well the patient remembers the answers.

As patients tend to see a different GP each time they visit, how will any changes be picked up, especially for patients who live on their own with no family to pick up any changes? Or people who do not visit a GP. How will these patients be referred?

If a patient continually does not attend for an appointment this will be picked up by the GP and the patient will be contacted. Receptionists are good at picking up changes in patients, especially ones that attend regularly, so they stop attending appointments or collecting prescriptions this will be picked up. Staff talk to each other so they will identify any issues, even changes in how someone is acting. Dementia Friends carry out dementia training and this highlights what to look for in people. Society is changing and people are becoming more dementia aware

LINKS WITH OTHER DISEASES

Is there a link between dementia and autism?

There is a link with downs syndrome and heart problems (i.e. vascular changes). There are specialist's Asperger's and autism teams within Somerset Partnership. Any testing for people with Autism would be supervised by the consultant clinical neuropsychologist to determine whether it is dementia or a reflection of their autism. For people with autism the focus would be on their family and carers rather than carrying out tests and different treatments would be tried.

What illnesses are known to contribute to the development of Dementias? Is there a connection with childhood illnesses, particularly Polio, many of today's older generations lived through the epidemics just after the 1939-45 war? Could it account for the big rise in numbers now?

Anything that affects someone's brain will increase their risk of developing dementia, although this is not a certainty, such as meningitis, encephalitis or lots of low level hits to the head, for example boxing or rugby or significant head injury following an accident. People with epilepsy are at more risk or people who have seizures as these affect the brain. The medical history would be looked into to find out how significant this was.

It is not known where there is a connection with Polio. Different generations have lived through different epidemics such as rickets and Aids.

LIFESTYLES

Would a family's way of life (lack of mental activity) have an impact on later life?

Anything that reduces the vascular risk factors for the brain is going to impact on long term life span and functioning brain health. People who lead a fit active life from a young age with lots of exercise, don't drink too much alcohol, don't smoke, stimulate their brain and have good social interaction will maximise their blood flow to the brain longer. This will mitigate the effects of vascular change.

Anything that reduces the oxygen supply to the brain could lead to a vascular dementia. Atrial Fibrillation is increasingly common; this is an irregular heart beat and results in tiny microscopic blood clots to the brain. Once there are enough of these patients can develop signs of a vascular dementia. Patients who have suffered a stroke, heart attack or had by-pass surgery could develop dementia. People who have diabetes can suffer a higher incidence of dementia if they have a poor control of their diabetes. Other diseases that will

have an effect on the brain over a lifetime are chronic obstructive airway disease (COPD), asthma or other genetic diseases. Modern medicines and general physicians and surgeons are brilliant, they can make people live longer with by-passes and drugs, but there is still a price to pay and it impacts on patients brains in the long run. Not everyone in these categories will go on to develop dementia but reducing the risk to your brain by maximising oxygen supply makes common sense.

Is there any evidence of difference in other parts of the world, particularly in respect of climate, diet and ethnic background?

Italians have a much lower incidence of dementia but their diet and culture is different; whole families live together and care for each other. If someone is diagnosed with dementia, changing to an Italian diet will not help as this has to be eaten for their whole lives to have any affect.

Recent research in Great Britain and America showed that people with certain dementias who interacted with small children (18 months to 2 years old) were helped as this stimulated their brains. There are other cultural factors in some countries it is seen as a mental illness. So in China it is seen as a punishment so patients would not visit their GP. This means that statistics are not necessarily accurate. People from black and ethnic minorities do not tend to visit their GP so they are hard to engage with.

PREVALENCE OF DEMENTIA

Is early onset Dementia becoming more common when compared to fifty or so years ago or are we able to diagnose it earlier?

There is a lot of publicity around dementia nowadays so more people are going to their GPs with related issues such as memory problems, starting to say things that are not appropriate, doing things out of character and having difficulties with speech. This is happening with younger people. Young men in particular are drinking more and this will have an effect on their frontal lobes. A lot of work is being done around education and working with people to reduce their alcohol intake.

The College of Psychiatrists produced a report recommending females drink a maximum of 14 international units (pub measure) a week and males drink a maximum of 21 international units per week. Adults over age 65 need to divide this by three as their cognitive function will be starting to deteriorate and the effect of alcohol will be three times higher.

In order for a realistic diagnosis to be made people need to reduce their alcohol intake as this will cancel out any medicines. This is down to individual choice and not a cure, but it will help people live in their own homes longer or for the rest of their life instead of going into a nursing home.

We are an aging population so there will more people will dementia. Society needs to be behind this and think about how people can be supported. Family support is very helpful but this can be difficult as families are more geographically spread these days.

Can young people get dementia?

From late 20's early 30's the brain starts to degenerate so technically that could be a dementing process. There are also certain mental Health conditions that would make someone more sceptical to developing a dementia, for example bi-polar, depression, psychosis, a long history of depression or anxiety. There are other genetic illnesses that could affect this as well.

Is there any evidence that dementia runs through families and can it be inherited?

Dementia can be inherited although this is only in about 6% of the population worldwide. This is typically in people presenting in their 30's, 40's or early 50's. In these cases we would look at family history to see if other members had developed dementia at a young age. If this is the case other family members would be invited to have genetic testing and counselling. There are now situations where more family members are developing dementia, but people are living longer so more older people developing it. The frontal lobes are usually affected first in younger people. Pure frontotemporal dementia is fairly unusual and does not initially affect memory.

There is a lot of dementia awareness these days so more people tend to present to their GP if they are worried about their symptoms.

DRUGS AND MEDICATION

Aricept is used to delay the symptoms of Alzheimers. Are there other medications with similar results when used for other forms of dementia and are different types of medication used to treat more than one type of the diseases.

A group of four drugs are used – Aricept (now known as Donepezil) and Rivastigmine (these are very similar), Memantine and Galantamine. Initially we use Aricept, as it been around longer and it is taken orally, once a day. Rivastigmine is very similar and would use for certain conditions, for example for people who have a lot of visual hallucinations or people in the Parkinson's spectrum of dementia. This drug is taken twice a day and the dosage can be managed. This can also be provided by a sticky patchy where the drug is absorbed through the skin and is suitable for people who have problems taking oral drugs.

Memantine is use for people whose frontal lobes are affected by dementia, their brain may be all right but their behaviour may change dramatically as the dementia increases. This drug does not affect the front of their brain and would be the first choice, instead of Aricept.

Patients are referred to a Memory Assessment Service, which is a team of memory nurses who contact the patient and their family every six to twelve months (depending on need) for a review and signpost them to other services. This is very important as drugs alone are not the answer.

Are Arthritis drugs used for some dementias?

Aspirin is often used as an early anti-arthritis drug and which helps thin the blood which prevents tiny blood clots in the brain, which will lower the risk of vascular dementia. There is a lot of research taking place into inflammatory changes in the brain and it is though that initial changes often start when people are in their forties.

**Do anti anxiolytic medications have a link to the development of Alzheimers disease?
Are people informed of possible side effects of medication?**

Anxiolytic is a drug that lowers anxiety, so anti anxiolytic would increase anxiety. Statistically you can link this. GPs see people who get anxious five or six years before they start showing signs of mental problems and will be referred to the Community Team if they cannot control the patients' anxiety. The amount of prescribed drugs is increasing. These people develop dementia at a later stage; their anxiety will lead to memory problems when they will know their world is not quite right. For example, they may decide stop driving if they do not feel quite right.

Do different countries use a different approach? Some use more physiotherapy for example; can you give a reason for not using it in Nursing Homes?

There is a shortage of physiotherapists and it is very expensive, so there are other ways this can be done. Dancing is good for people with dementia; whilst they may forget the words to songs they often remember dances from their youth. People with dementia need to exercise, not just to sit down, as this will get the blood flowing.

They need to keep their skill levels up, so let them do things for themselves whilst they are able to, once they stop they will lose this. This happens when people go into hospital as everything is done for them so they will lose this ability.

FUNDING AND RESEARCH

Has funding to charities increased and how much is passed on to direct research projects?

The voluntary sector will probably be more involved in some areas as they are in a good position to bid for services when they are put up for tender. The third sector are being looked at to become more involved as they are very valuable. One example is social isolation, it can be very lonely for people with dementia, especially if they live on their own, so this is an area that can be developed and there are huge opportunities.

The development of new drugs is an extremely expensive operation with a very risky chance of return. This often deters drug companies primarily as patent rights cover such a short period. Could the period of cover be extended to give an initial reduced cost and over the longer period make the investment worthwhile?

Pharmaceutical companies make a lot of money during the lifetime of a patent and when the patent expires.

Even without changes to patient law the NHS (being the bulk of the UK market) could possibly negotiate longer contracts in order to reduce the ongoing price. Is this done now and is it possible?

Polypharmacy is giving a huge number of drugs to patients that they don't necessary need; there is pharmacy support within the community for care homes. GPs are getting better at looking at individuals and prescribing the best drugs for them rather than following best practice, but this can sometimes be difficult as GPs are measured on this.

Dementia and other lifelong Mental Health conditions, make demands on individuals and their families, primary care, specialist services and hospitals NHS, particularly when accompanied by other morbidities. The thrust is for the Local Authority to strengthen personal and community preventative support. How are these delivered, without ring fencing, by a Local Authority already diminished after many years of cuts and more to follow?

All Local Authorities have had cuts in funding, so we have to make the best use of public sector resources. The first part of the CCG five year strategy is looking at how to get people to look after themselves and keep well to prevent them from becoming ill. People get long term conditions need to look after themselves and need support, especially people with dementia and carers. There are small communities in Somerset where people get to know each other and can support each other; this has to be encouraged as there is less money for services. Where there are good support networks this helps people live longer in their own homes instead of going into nursing or residential homes. The Mulberry Centre uses networks and if this can be expanded along with education that would be a useful source for information that can be shared.

There is not a cure for dementia so people have to learn to live well with it as it can be a long time before they get really poorly. One example is to get people to write things down so they can remember things and encouraging friends and families to use this system as well.

Living longer seems to indicate mental decay but as not everyone becomes a victim and there are different types of dementia it seems to prove that they are major illnesses deserving the same consideration as other major illnesses. Would you agree? Including research funding?

The Prime Minister's Dementia Challenge identified funding for research and this has improved. Somerset CCG was successful in gaining some funding for a Dementia Friendly Community Project in the Chard, Ilminster and Crewkerne area and was used for the following initiatives:

- developing local networks to improve awareness of dementia through forming Dementia Action Alliances in the towns
- Implementing Archie the Scarecrow project in primary and middle schools
- implementing a befriending scheme that offers a vital lifeline and opportunities for people to continue to engage in local activities with trusted support
- building on existing training programmes so people receive personalised care enabling them to make positive choices
- improving the hospital experience for people with dementia and their carers