

# World Alzheimer's Day Bulletin

21 September 2001

## Diagnosing dementia: the first step to help

**T**he diagnosis of dementia comes as a shock. But naming a person's symptoms helps to demystify and destigmatise their condition and may also resolve their anxiety, as well as that of their family. It can maximise a person's quality of life, give a person a greater chance of benefiting from existing treatments, allow the person with dementia and their family access to resources and information, and provide more time to plan for the future.

It is a common assumption that making a diagnosis involves a series of expensive, hi-tech clinical investigations. This is not true for dementia, where the most important part of diagnosis is listening to the person's story of the development of dementia.

Of the 18 million people currently in the world with dementia, about 66% live in developing countries. As the world's population ages and the number of people being diagnosed with dementia increases, more people will be turning to Alzheimer associations for help.

Alzheimer associations are dedicated to providing support to people with dementia and their families. They provide:

- Practical and emotional help such as helplines and support groups
- Information
- Advocacy to governments
- Training for carers and professionals
- Services such as respite care



George and Dorothy Brown

### Sharing the news

About four years ago, George Brown (then aged 73) visited his doctor about his failing memory. The doctor showed little interest and said his condition was normal memory deterioration. Following continued deterioration, George returned to his doctor at the beginning of 2000. After much reluctance, George's doctor referred him to a specialist but questioned what difference a diagnosis would make when there was no cure for Alzheimer's disease. George and his wife Dorothy describe below why having a diagnosis has been important.

#### 'Life has become much more tolerable'

##### George Brown

*'I was diagnosed as having the early stages of Alzheimer's disease. While this was a terrible blow to both myself and my wife, we were glad to have been told so that we could discuss the possible effects on our lives and plan how we could adjust to the situation.'*

*I have made an Enduring Power of Attorney and a will.*

*I think it is important for the partner of the person with dementia to be fully informed of the diagnosis and possible effects since the partner's life is affected quite dramatically also. Fortunately for me, my wife is an intelligent and caring person with a strong personality. We have had 54 very happy years together and she is most supportive.'*

##### Dorothy Brown

*'We were together when George was given his diagnosis and we were both reduced to tears. However, life has become much more tolerable since we can understand why things are happening. It is easier to accept things because they are unavoidable. I am quite sure that if my husband had not been told we would not be able to carry on. As it is, we discuss every aspect of his illness and make as many plans as we can for the future.'*

*We enjoy our life from day to day and we are far from miserable. We don't know what is to come, of course, but I'm pleased that at the moment we can at least share our problems and delights.'*

[www.alz.co.uk](http://www.alz.co.uk)

Every person reacts differently to the news of a diagnosis. There is no right or wrong way – only your way. The following comments have been made by people from around the world highlighting some of the emotions that are experienced upon receiving a diagnosis of dementia.

**Margarita Padilla Sellean, who has Alzheimer's disease (Peru)**

*'Forgetfulness is awful'*



# What a diagnosis

**Felisa Ibañez, who has Alzheimer's disease (Mexico)**

*'Everyday that passes I feel lonelier in a world that I can't understand anymore. It is good to know what I have, although I can't always understand it. The best thing is to feel loved and to have friends. Please do not leave me alone.'*



**Leszek N who was diagnosed with Alzheimer's disease at 71 (Poland)**

*'Help me enjoy my life'*



**Ellen Agger talks about her mother Molly Blake's diagnosis (Canada)**

*'I watched my mother struggle to find words, manage her medications, prepare food. A diagnosis of dementia (probable Alzheimer's disease) helped both of us put plans in place for her care. It also prepared me to better advocate for her when she was no longer able.'*



**Catherine Siow and her mother (Malaysia)**

*'My mother was diagnosed with Alzheimer's disease in July 1998. The diagnosis cleared a lot of my fears and anxieties when I didn't know what was happening. It helped me prepare myself to give better care to my mom. I also believe that the early diagnosis and drug prescription helped plateau off the deterioration of her early stage Alzheimer's. With the diagnosis, I felt that I was doing 'enough' and giving my utmost best in caring for my mother and I felt good about it. It lessened the overwhelming guilt that built up over the period before the diagnosis.'*



**Ronald Reagan announcing his diagnosis of Alzheimer's disease 5 November 1994 (USA)**

*'I have recently been told that I am one of the Americans who will be afflicted with Alzheimer's disease. At the moment I feel just fine. I intend to live the remainder of the years God gives me on this earth doing the things I have always done. I will continue to share life's journey with my beloved Nancy and my family. I plan to enjoy the great outdoors and stay in touch with my friends and supporters'*

# has meant to me...

**Mary (India)**

*Mary is 94 and was diagnosed with Alzheimer's disease one year ago. Her diagnosis has meant she has been able to attend a day centre.*



**Adele Joaquin and her family (Philippines)**

*'Had I known earlier my mother had vascular dementia, I could have brought her to the doctor at once for proper care and medication. The problem was we always thought this was a normal part of ageing.'*



**Christine Boden, who was diagnosed with Alzheimer's disease at 46 (Australia)**

*'I felt as if time had stood still – surely this wasn't happening to me. I must have misheard – he was mistaken, the scans maybe had got mixed up with someone else's... You're joking, I'm too young to get Alzheimer's!'*

Extract from her book *Who will I be when I die?* (1998)



**Alzheimer's Disease International**

# What's in a diagnosis?



## What is diagnosis?

- Naming the disease
- A guide to outlook
- A guide to treatment

## What does diagnosis involve?

### Describing the symptoms

Assessment goes beyond diagnosis and includes a description of the symptoms experienced by an individual, an estimate of the severity of the condition, attention to the physical health of the person, the person's emotional needs and those of the person's carers.

### Naming the disease

Memory loss, difficulties with ordinary activities of life, changes in personality – these are the common symptoms of dementia. They are disturbing, sometimes frightening and always worrying signs. But what do they mean? For carers and for people with dementia, a diagnosis of dementia is the first step towards understanding and towards care. Diagnosis is essential for all of those touched by dementia. This applies to doctors as much as patients.

### Conveying information about cause, outlook and treatment

A diagnosis carries information – about the cause of the condition, the outlook and the possible treatments. In the future, as our understanding of the different dementias grows, the information carried by diagnosis will be greater.

## Why diagnose?

### For the person with dementia a diagnosis:

- Conveys information about cause and outlook
- Provides an opportunity to discuss the problem and the future
- Initiates access to resources and treatments

### For the carer and the family a diagnosis should provide:

- Recognition of the carer's role
- Access to resources and support
- Information
- An opportunity to discuss outlook and practical arrangements

### For the clinician and providers of dementia services, diagnosis:

- Creates a professional and therapeutic bond between the doctor and the patient
- Is essential for communication between professionals
- Can encourage funding of dementia services

## What causes of dementia are there?

Dementia is a clinical syndrome arising from a number of different causes. No matter what the cause of dementia, each cause results in a decline in mental function, especially memory. Dementia interferes with daily activities and social relationships and usually runs a progressive course although it can be stepwise. Dementia is usually irreversible and ultimately fatal. The most common causes include:

### Alzheimer's disease

- Accounts for 50-60% of all cases
- Widespread damage to brain tissue
- Slow decline of memory, language and thinking

### Vascular dementia

- Damage due to poor blood supply to brain cells
- Stepwise decline of memory
- Other signs of vascular disease eg strokes

### Dementia with Lewy bodies

- Special abnormal appearances in brain tissue
- Fluctuating memory problems
- Distressing hallucinations (visions)
- Stiffness and slowing of movement (parkinsonism)
- Falls

### Fronto-temporal dementia eg Pick's disease

- Local damage in front part of brain
- Slow onset of memory loss
- Early deterioration of social behaviour and personality
- Language deficits early

## Who needs to know the diagnosis?

### People with dementia

- Can often understand and discuss the diagnosis
- May recognise there is a problem and want to know why but carers may wish to protect their relative from distress caused by telling the diagnosis
- Clinicians and other professionals can find it difficult to discuss the diagnosis and may need training and support

### Carers

- Should always be informed – but also remember other family members
- Are supported if the diagnosis is discussed sensitively with them
- May find it helpful if the diagnosis is explained to the person with dementia
- May require time and repeat visits

### Other members of the team

- Different types of professionals may be involved ie physicians, general practitioners, neurologists, psychiatrists, social workers, nurses. They should all work closely and share information, as good communication between professionals is essential in dementia care

## Four steps to making a diagnosis

### 1 Listening to the person with dementia and their carer

The first and most important step of diagnosis is the story of the development of memory loss and other impairments as described by the person with dementia and someone who knows the person well, usually a spouse or family carer.

### 2 Recognition of memory loss and other symptoms

Improving recognition of memory loss and other cognitive problems is key to improving diagnosis. This improved recognition of the problem can be achieved by screening – the routine testing of mental functioning by family doctors or general practitioners, or other health professionals. The public has a vital role too – we need to increase awareness that memory does not normally disappear with ageing and that poor memory should be investigated at any age.

### 3 Describing the syndrome of dementia

The third step in the process is to determine why the problem has occurred. Is it due to dementia or another problem? If it is dementia, what is the cause? This third step is one of the most important as many of these non-dementia causes of cognitive problems are readily treatable and rarely some of the dementias may be reversible.

### 4 Diagnosing the disease causing dementia

The pattern of decline, the kind of symptoms present, the findings on tests of memory and other cognitive functions and investigations can usually determine which disease is causing the dementia with a good degree of accuracy. With increased awareness and better training it is hoped that more primary care professionals will be able to do this.

## How can we improve diagnosis?

### Make the diagnosis earlier

An early diagnosis allows early support and early intervention. This is important now and will become more important as treatments get better.

### Make diagnosis the starting point and not the finishing point

A diagnosis must be accompanied by support for all concerned. Support means information and counselling, as well as comprehensive services and appropriate treatments.

### Make it more accurately

Diagnosis is accurate now but not accurate enough. Accurate diagnosis relies on the clinical skills of effective listening and examination.

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## Feedback

We would welcome your comments to any of the issues raised in this bulletin. Please contact us at:

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