

# Dementia care: how we get it wrong and what's needed to get it right

Many clinicians are relying on an out-of-date medical model in their diagnosis and care of people with dementia, according to **Dr Jane Tolman** and **Dr Martin Morrissey**. Here they share their views about how the medical profession can better support individuals with dementia and carers

**W**e are doctors. We specialise in the care of older people, and between us we have been diagnosing and managing dementia for 30 years.

But we trained last century. And, it seems to us, our training did not anticipate the skills required to meet the challenges of 21<sup>st</sup> century medicine.

In the 19<sup>th</sup> century infectious diseases were the predominant illnesses. In the 20<sup>th</sup> century, as life expectancy increased, cancers and vascular diseases overtook as the most common causes of death.

But, in the 21<sup>st</sup> century we are entering the era of neurodegeneration. With increasing life spans, we are living long enough to suffer from, and die of, a new range of conditions – those relating to the degeneration of the nervous system. Neurodegenerative conditions include Alzheimer's disease and other forms of dementia, Parkinson's disease, motor neurone disease and many others.

We believe that the journey of dementia, the most common of the neurodegenerative conditions, is made unnecessarily difficult because many health professionals are yet to catch on to these changes.

## Neurodegeneration and medicine

How has the era of neurodegeneration changed medicine? Firstly, in the past an individual could reliably have been expected to be cognitively 'normal' and capable of making decisions, with the clinician, about the course of treatment. This is no longer true. As dementia progresses, almost no person will retain the capacity to make decisions relating to anything complex.

Secondly, the goal of care was, predominantly, curative. Neurodegenerative conditions, however, follow a progressive course ending in death. There is no cure. There are no disease-modifying medications. It's now all about managing the 'journey'. The emphasis should be on palliation, by which is meant an emphasis on symptom control and quality of life rather than cure of disease. The 'journey' needs to be managed and planned. Critically, treatment is about maximising the quality of life. What constitutes that quality changes as the dementia progresses. By its very nature, dementia often robs the individual of appreciation of what constitutes enjoyment. The carer's role is paramount.

Thirdly, the diagnosis of disease was once easy. The particular test required was identified and we could expect a positive or negative answer. This

went for asthma (lung function test), a stroke (brain CT), HIV (blood test). The diseases of neurodegeneration are diagnosed by clinical acumen. Doctors use three tools in diagnosis: the history, a clinical examination and investigations (tests). A history (what's been happening) has always been very important. But in the era of neurodegeneration, the history is critical to making a diagnosis. And since the person with the condition is very often not 'normal' cognitively, the history will come from family and carers.

Fourthly, the course of many chronic diseases – such as arthritis or heart disease – is long, progressive and will cause disability. These chronic diseases are rarely characterised by major shifts in personality, do not routinely affect relationships with loved ones, and rarely have such diverse symptoms as neurodegenerative conditions.

These affect physical and cognitive abilities and will inevitably lead to disability and dependence. Daily swings in function are characteristic and difficult for carers to understand. In our experience, carers need considerable resources in support of their very challenging roles. That support should always include education about what's involved along the way.

## Out-of-date medical model

Clinicians have failed to appreciate these features, as they have not typically been privy to the story people with dementia and their carers live. It seems to us that some clinicians have failed even to appreciate what dementia involves, using as their framework the out-of-date medical model described in the four points above.

Unlike chronic diseases such as diabetes or rheumatoid arthritis, one of the core features of dementia is deterioration in the cognitive skills essential to our day-to-day functioning and decision making. An individual's capacity to make informed decisions may have deteriorated even prior to the time of diagnosis.

In light of this, involvement of a proxy decision maker / person responsible / guardian will be necessary as the dementia progresses, and in many circumstances will be appropriate from the time of diagnosis. Patient confidentiality is an expected and legislated component of the interactions between the patient and clinician. Refusal by a patient to permit the clinician to share information with a third party, however, is only valid if the refusal is competently made. Clinicians must



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# The five domains of dementia

Too often, dementia is equated to a problem of memory. To those who care for someone with dementia, this may be the very least of it. So what abilities does dementia affect and what are the symptoms?

## 1. The cognitive:

- memory
- insight (appreciation of what's going on and the consequences of this)
- reasoning
- judgment
- planning skills
- empathy for others
- orientation in time and place
- language use.

## 2. Function:

- driving
- cooking
- computer skills
- use of the television controls
- microwave and stove.

## 3. Psychiatric:

- delusions (false beliefs or ideas such as those relating to persecution)
- hallucinations (false perceptions: visual, auditory or even olfactory)
- depression.

## 4. Behavioural:

- intrusions into another's space
- repetitions
- screaming
- persistent or relentless walking
- aggression
- sexual disinhibition.

## 5. Physical:

- mobility
- continence
- swallowing problems
- loss of interest in eating.

therefore make some assessment of a person's decision-making capacity when deciding about discussing care with a third party.

We continue to encounter situations in which health care professionals have been unwilling to discuss a patient's care with a family member or other appropriate concerned party, due to a misguided understanding of patient confidentiality. This not only goes against what might be the best interests of the patient; we would assert it represents inadequate patient care.

## Importance of palliative care

In caring for people with incurable cancer, principles of palliative care are now widely practised within medicine and more broadly accepted by the community. For many people with cancer there may be a period of time where cure is the expectation. During this time it might be reasonable to accept unpleasant or complex treatments or prolonged periods of hospitalisation.

Dementia has no cure – at diagnosis it is always equivalent to an aggressive, treatment-resistant cancer with multiple metastases. Yet despite this, health professionals have been very slow to embrace the concept of palliative care in people with dementia. We see this as leading to relatively minor, inappropriate treatments, such as continuing a cholesterol-lowering medication in

an 89-year-old person with advanced dementia who is bed-bound.

But it also leads at times to far more serious and ultimately detrimental management. We have seen people with advanced dementia brought into hospital for complaints which would have been best managed at home. Almost invariably, these patients suffer major complications such as lost mobility, pneumonia, premature residential aged care placement and even death. We have witnessed considerable suffering by people with dementia who were subjected to major surgery when the prospects for an improved quality of life were always poor, and the risks of post-operative complications, such as prolonged delirium, were high.

From a wider health care perspective, hospitalisations and investigations in the final stages of dementia cause suffering for the individual – and carers – and place a significant burden on health resources.

To help guide health professionals and carers, we have identified a list of the symptoms of dementia (see box, left), many of which people will not recognise, but each of which may have significant effects on well-being and the quality of a person's dementia 'journey'. We also outline below the three stages of the dementia journey.

## The three stages of dementia

The 'journey' of dementia is lived by the person with the condition, but the journey is also very much that of the carers. Due to both physical and cognitive deterioration, carers are almost always essential at every step along the way. When carers are not part of a team, care is compromised. Understanding the journey means also being able to anticipate what's coming up.

Here, we present a system of staging dementia which is very focused on the carer journey, and we believe that it promotes greater carer satisfaction by means of empowerment. Increased knowledge about dementia will also improve the relationship between the carer and the person cared for, and this will improve the quality of life of the person with dementia. No two people with dementia will have identical symptoms, but it is possible to outline significant features of each stage of their journey so that these may be anticipated and better support provided for the person with dementia.

## The first stage

We define this as the time in which a person can be supported while living at home after diagnosis. This will involve a decline in function and relationships, partnered with an increase in the support required from carers. But there is scope for a focus on maintaining, and even improving, quality of life. The goal, simply defined, is to support the person to remain in this stage for as long as possible, and to have the very best quality of life while doing this. This leads us to appreciate what carers need to do, namely:

- Ensure that medical assessments are done and that all (and only) appropriate medications are taken. The fact is that hospital admission is to be avoided if at all possible; it is likely to accelerate the

person's decline and hasten permanent placement.

- The residence should be assessed for safety, preferably by an occupational therapist. A fall or unsafe behaviour may have catastrophic consequences.
- In view of the person's declining cognitive capacity, the physician should communicate with the carer(s) to monitor progression.
- The physician should be aware that the decline in cognition will lead to a loss of decision-making skills. The role of the carer is to communicate a *trigger* to the physician so that capacity assessment is done when required. This trigger might be the need for a legal decision, a choice about a medical matter such as surgery, or a change in accommodation needs.
- The identity of the decision maker (the person with dementia or, later on, a surrogate) should be clear at all times, and whenever possible made part of the management record.
- It is vital that carers are alert to sources of enjoyment for those with dementia. Supplying an environment, and activities, which enhance the quality of life will be the responsibility of the carer. This may be confusing or confronting, as there will inevitably be changes in those sources of enjoyment, and they must be balanced by safety considerations.
- The carers should be well informed about the nature of the condition and the path ahead. This includes identification of deterioration in the person's condition as it occurs, and preparation for the next stage. In Australia this will almost invariably mean a review by the Aged Care Assessment Services.

### The second stage

During this stage the person with dementia needs 24-hour care. As care needs increase, typically the person will move into residential aged care. In some cases the use of extra services or family support within the home may be appropriate. The precipitant for 24-hour care may be the carers' inability to continue supporting the person, or the failure of the current arrangements to provide a safe environment.

The goal now is to provide safety and support the person to maximise enjoyment. When enjoyment is possible for the person with dementia, this should be sought.

- Medications should be reviewed regularly to eliminate futile treatment or treatment which might cause more harm than good.
- Plans should be drawn up to minimise the need for unnecessary hospital transfer. Ideally, medical care should be provided in most circumstances within a care facility. Transfer to hospital is often a terrifying and distressing experience for someone with dementia – and a source of great frustration for carers. Hospital treatments will often be seen as inappropriate or even harmful.
- Care plans should be arranged through a collaboration with family/loved ones, care staff and medical professionals. It is imperative that carers are included at each stage of decision-

making. Informed members of this collaboration will be anticipating what's ahead and be able to identify the emergence of the next stage.

### The third stage

This is reached when those involved in the person's care are unable, by agreement, to identify that the person is experiencing significant enjoyment in life. This is not a matter of any one personal opinion, but of the collective sense by the team. The goal in this stage is to ensure that the individual's distress, whatever its source, is relieved. During this stage, some people will be mobile. Others will be bed-bound and totally dependent on carer support.

When there is no perceived suffering, then best care includes a focus on personal interaction as well as attention to hygiene, hydration and nutrition. There should be exposure to sunlight and nature. We recognise that although a person in this stage of dementia may no longer be capable of recognising flowers or music, for example, their presence will enhance the environment, and even the simple act of supporting someone to eat and drink at mealtimes can be nurturing.

When distress is identified, however, the emphasis should be on its relief.

When a trigger for the distress can be identified (pain, anxiety, delusions, infection etc) this should be treated or reversed.

When no trigger can be identified, when its treatment fails to provide relief, or when treatment is futile, then comfort care should be commenced. This will include any treatment whose goal is to provide relief of suffering, even at the expense of prolonging life.

### Points for practice

- Carers play a critical role in the journey of dementia, and their role needs to be acknowledged at every step.
- A diagnosis is critical to best care, and this requires input from carers.
- Best practice in dementia care mandates a collaboration between families, informal carers, health professionals and paid carers. This may challenge clinicians whose practice has been based on a 20<sup>th</sup> century medical model.
- The goal of care in dementia changes over time. When carers are informed about dementia and its progression, changed care needs will be anticipated and managed. There should be no surprises for a carer, especially as the person they are caring for nears the end of life.
- Identifying who is the decision-maker in the life of someone with dementia is a must if poor decisions are to be avoided. This can only be done when the health professionals engage with carers.
- We believe that the five domains and three stages discussed in this article provide the framework within which care can be maintained appropriately during this ever-changing condition.
- Hospitals rarely have much to offer a person with dementia, and care is best provided in the community by well-informed carers and health professionals. ■