

Trained attendant orientation note for dementia care

Scope: This note provides a simple, first-cut introduction to dementia and essentials of care. It is intended to provide families a basis to start checking whether the attendant knows the basics and training the attendant. It should be modified as required by the family, so that it fits the reality of their patient's state.

How to use the note:

Review the note and examine how it fits your needs. Print it out, and mark changes. For example, the note calls the patient as "Amma", and you will need to change "Amma" to the relevant title. Use the blank right-hand-side column to add comments, translations, and examples, to make the note suitable for your patient's situation.

While explaining, use simple terms in the local language. Emphasize the physical aspect of the damage to the brain by repeatedly using the pictures included. Provide the attendant with a translated copy or let the attendant note the points in his/ her language. Give the attendant a printout of the pictures to emphasize the points and act as a reminder.

You can also supplement the explanations with videos available online (including some in Indian languages); see <http://dementiacarenotes.in/resources/videos-and-presentations/> for a selection of such links)

You will need to repeat this orientation a few times, and supplement it with information on the patient's other medical problems, and with specific tips and instructions for tasks to be done for the patient, and his/ her specific likes and dislikes. Encourage the attendant to ask questions.

In addition to telling the attendant how to communicate with the patient or help with various activities, ensure that the attendant knows that there could be problems in spite of the best of efforts. Modify the note to include typical problems faced. Assure the attendants that they will get a chance to explain their point of view to you later and that they shouldn't argue with the patient, or complain in the patient's presence.

The note follows on the next page. There are two parts:

- Part 1: The simplified explanation
- Part 2: The pictures to illustrate the brain (pictures used are for Alzheimer's Disease, but are graphic enough to be used to explain dementia in general)

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Part 1: Simplified introduction to dementia and care

	Notes/ examples/ translations
Amma has an illness that has shrunk her brain. She has symptoms called "dementia."	
Dementia is a problem of the brain, like heart problem is a problem of heart	
Her brain has shrunk. It has changed physically and these changes are causing problems. There is no cure. It will only get worse.	
Normal people have brains with lots of cells called neurons. Neurons are needed to <ul style="list-style-type: none">• Remember things• Think about things• Speak correctly• Understand things	
In dementia, neurons get damaged. Also, some neurons die, so there are fewer neurons. (See the picture on the last page)	
Therefore, Amma gets very confused	

	Notes/ examples/ translations
She gets especially confused about recent things, like whether she has eaten	
She uses wrong words, like saying the pain is in the head instead of stomach	
She forgets what people tell her. For example, if you tell her you will come back in five minutes, she may forget that.	
She forgets what is good for her. So she may do things that harm her, like taking off her sweater even if it is very cold.	
She cannot understand anything easily	
Because of all this, she gets very sad and frustrated	
And sometimes, she gets worried and angry	
If she wants something, she does not know how to ask for it	
This makes her sad	
Sometimes, she gets angry and shouts	

	Notes/ examples/ translations
Dementia even affects her ability to control her feelings. So once she gets angry, she is not able to calm down for some time, even if she has forgotten why she got angry.	
On some days, she can manage to act normal in spite of her problems; on other days, she faces more problems. She gets upset and forgets more and is not able to do things.	
She is very slow in doing things, because her brain has been damaged by dementia	
She is slow in getting up. You have to be helpful but patient	
She is slow in speaking; you have to help by pointing at things and making gestures	
But she understands emotions	
When she sees you or hears you., she knows of you are angry or irritated or sad	

	Notes/ examples/ translations
If you are angry or irritated or impatient, she also gets angry and worried	
She thinks that any loud voice is like a scolding or anger	
If you are calm, she becomes calm after a while	
She can be very affectionate if she is calm	
<p>When talking to her, remember:</p> <ul style="list-style-type: none"> • Talk slowly • Talk softly but clearly • Use simple sentences • Give one instruction at a time • Repeat if she looks blank (but stay calm) • Touch things/ make gestures/ point out and explain • Look peaceful 	
Give her time to do things; remember, she is slow because of her illness	

	Notes/ examples/ translations
Nod to show that you understand. Nod to reassure	
<p>If she gets angry/ frustrated/ worried/ complaining,</p> <ul style="list-style-type: none"> • stay calm • remember she is ill • try to understand what is bothering her • distract if it is unimportant • nod and show you understand • reassure <p>Call us if you are unable to handle</p>	
DO NOT get angry/ worried	
DO NOT get sad	
Her behaviour may look odd to you, but it is normal for dementia patients	
Sometimes she will get angry even if you have not made any mistake	
Do not complain about her in her presence	

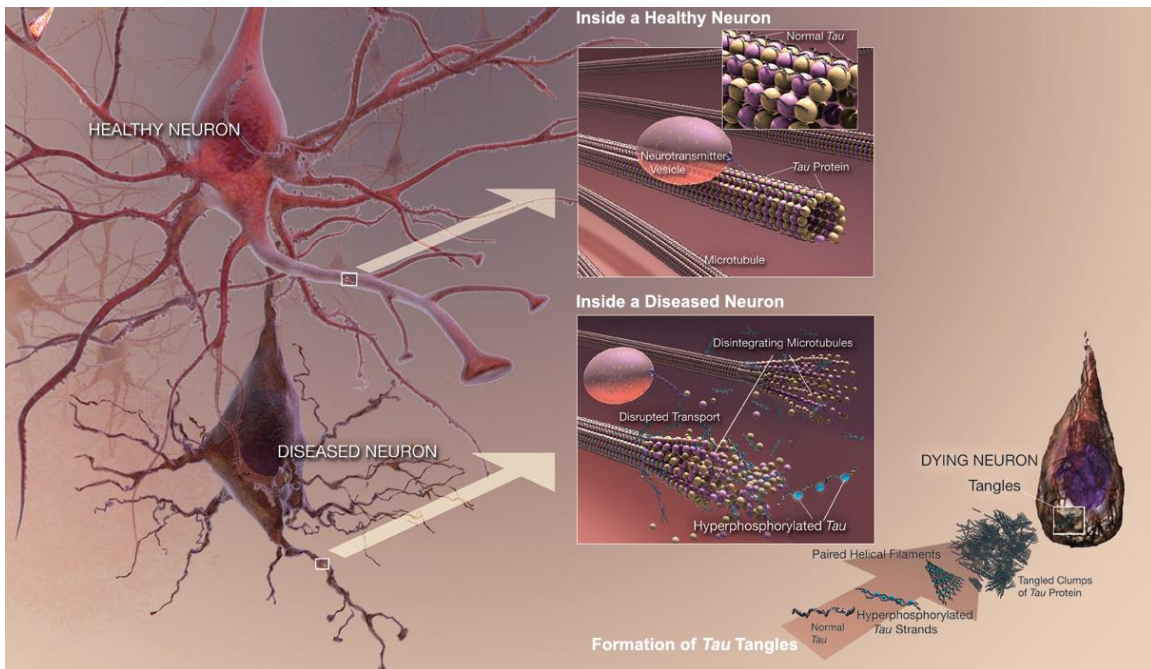
	Notes/ examples/ translations
Do not argue with her or try to "correct" her; that only makes her feel worse and she gets more upset	
If she is complaining, stay quiet. We (the family members) know that she may be complaining because she misunderstood something, because of her illness. We will talk to you later to find out what happened	
If you complain about Amma when Amma is there, or if you try explaining when she is listening, she will get more angry	
We have faced all these sorts of problems and so we understand	
We will discuss this later and explain how you can handle things	
Dementia patients confuse between reality and imagination	
Do not worry	

	Notes/ examples/ translations
Just remember this behaviour is because of an illness. Amma will be easier to work for if you are calm and talk to her in ways she can understand easily.	
Even if you make a mistake, do not worry	
We all make mistakes	
But you must tell us the truth of what happened, so that we can explain how you can avoid the mistake next time	
Remember, Amma can be very affectionate when she is calm and happy	
Our job is to try and make her remain that way	
We help her and try to make sure she does not get frustrated or sad or angry	
Sometimes, we play games with her or sing bhajans; she enjoys such times	

	Notes/ examples/ translations
We do not expect her to play games properly or remember the rules, but we can still enjoy spending time with her. We will show you how we do it	
Do not confuse this horrible illness with old age. Look at the pictures, and see how her brain is different from normal brains because of the illness	
Remember these points, and looking after her will be easier	
You may even be able to enjoy her company and feel her love	

Part 2: Pictures

Healthy Brain Severe AD



Images are courtesy of the National Institute on Aging/National Institutes of Health; images depict healthy brains and brains affected by Alzheimer's Disease (AD)