Chapter 1

Communication

Sometimes it's a struggle

We communicate to get a message across to others, to share ideas with others and to find out what others think and feel, to build intimacy, to share and solve problems. Without the ability to communicate we struggle to maintain a sense of relationship, connection and psychological attachment to other people. This is the difficulty faced by many people with impairment in the area of communicating. They struggle to make us understand their inner experience, wants and needs, and they struggle to understand what we want of them. We struggle to understand them and get our message across to them. The struggle is fraught with frustration and, at times, tension; it can be wearing and numbing. And then there are those moments of pure joy when both seem to be thinking of the same thing, each connecting with the other person and finding understanding. It seems so easy then.

How we communicate has a profound effect on the quality of our relationships, on the quality of our lives. Whether you are a spouse or a paid carer, if you have a relationship with someone who has dementia you may be experiencing some of the difficulty of communicating with your partner, loved one or friend, or client. (For

those readers working with a person with an intellectual impairment, simply change the words relating to dementia and replace them with words that match your situation. I hope this works for you.) It is not easy to maintain an equal relationship, as the dementing illness progressively affects the person's ability to contribute equally to the relationship.

The person-centred approach to communicating can keep the focus on the person and the dementing illness takes second place.

Before we go any further we need to look at how the healthy brain works and what happens when the brain is affected by dementia. In the next section we will look at the brain, how it functions and how it helps shape our experience of the world. Then there are a few questions that will test your understanding.

Dementia and the brain

The person-centred approach values all aspects of the person and this includes the biological health of the person, especially their brain. A normal brain does miraculous things to make us successful in our lives. Take a moment to think about all the decisions you have made today. You woke up, got out of bed, chose some clothes to wear, dressed yourself, ate breakfast; drove your car, walked, cycled or took public transport to work.

This marvellous brain sits in your skull cavity and is made up of billions of cells called neurons that send electrical and chemical impulses (messages) throughout

the brain when sensory input comes in, and often, in response to your imagination, memory and feelings.

When your brain functions as it usually does, you can think, remember, solve problems, feel emotions, use imagination, speak and understand the speech of others, recognise objects in the world around you, and much, much more.

When the brain is affected by a disease (such as Alzheimer's) or a malfunction such as a blockage to the blood supply, or by an injury, we begin to experience life differently and may in time act differently.

If the person you care for has Alzheimer's disease the first signs you may have noticed are memory problems and some difficulty finding words. The most obvious issue about Alzheimer's is that it is progressive, i.e. the difficulties gradually become worse over time. In the early stages the person may become lost and have trouble finding their way to places that were once familiar. You will find excellent information in some detail in your Alzheimer's Association help sheets and resources from other organisations that you can find quickly in a Google search. Check the quality of what you find, as it may be written by a recognised authority, or it may not. If it is written by a university or by a recognised agency you are familiar with, you can usually trust the quality of the information.

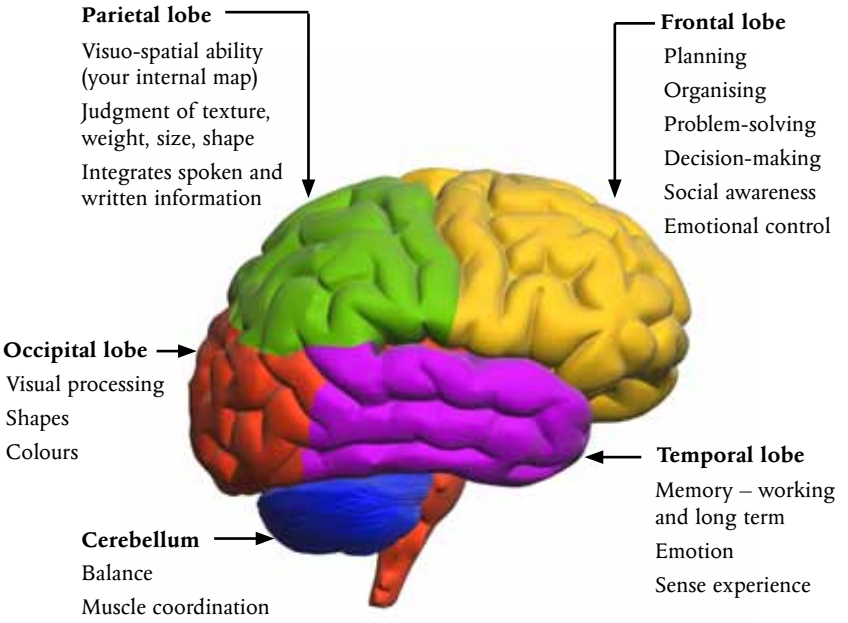
What is most important at this point is that you stay in touch with and be sensitive to the person's feelings about what is happening to them. Each person will react in a way that makes sense to them. Or put another way, each person makes sense of the world as they perceive it to be.

This is important from the person-centred approach. Valuing the individual person's perspective helps them to maintain their social self and remain successful as a social being for as long as possible.

For example, forgetting things may not be a problem emotionally to some people, but to others it may mean that they are a failure or a bad person. This may be so if they have had bad experiences of forgetting things as a child and been punished for it, as many people were. So tune into the emotional aspect of what is happening to the person when they forget, not just the obvious part (the forgetting) that you can see.

Hemispheres of the brain

There are two halves to the brain, joined in the centre, much as a cauliflower is made up of florets that are joined at the stem. Each half is believed to perform slightly different functions. One of the most important and clear differences is in language. The left hemisphere has more logical and structured thinking. The right hemisphere has more creative and expressive activity. The left hemisphere has more language function for right-handers (about 90%) than left-handers (50%).



Lobes of the brain

There are four sections or 'lobes' we commonly talk about: frontal, parietal, occipital and temporal. Another major area is the limbic system. Brain function is a 'team' activity in which each part works with the help of other parts to produce our experience. Some areas are specialised for particular functions – for example, the temporal lobes for memory and the occipital lobes for vision. Let's look at each of the lobes.

1. Frontal lobes

Frontal lobes are just behind your forehead and are very important for shaping social behaviour (knowing how to act in the company of other people), problem-solving, abstract thinking (being able to think about ideas like

'safety' or 'morality'), ability to start and stop doing or saying things, knowing how other people feel and adjusting our behaviour to them, and making decisions. This is the 'executive', the manager that helps us control ourselves and relate with others in the world in a safe and sociable way.

The frontal lobes are not fully formed until our mid-20s, which explains why some teenagers take risks and behave in ways that frustrate and concern their parents.

The frontal lobes also help us do complex tasks, such as dressing, in the right sequence of steps.

> Sarah had trouble dressing in the right order and each day walked into the dining room with her underwear over the top of her tracksuit. One day she had been to the hairdresser and walked into the dining room clearly feeling very good about herself, as you do after having your hair done, carrying her handbag and with her undies over the top of her tracksuit. The staff member came up to her and said very discreetly, 'Sarah, you've got your undies over your tracksuit'. Sarah turned around, and with hands on hips said, 'That's how we wear them here!'

2. Temporal lobes

Temporal lobes are very close by, on either side of your head in front of the ears (in the temples), and are mostly important for memory. Modern knowledge of memory is much better now than in the past. We used to talk about short-term memory, but now use the term 'working memory'. This relates to the ability to hold pieces of information in our minds long enough to do something

with them, i.e. work on them. An example might be learning a phone number or making a shopping list, or remembering a person's name in a conversation so that we can use it again at the right time.

Long-term memory, on the other hand, is the ability we have to store information/experiences/knowledge for long periods – up to a lifetime. We can usually do this by repeating the information often until it is 'learned'. Then we can retrieve it again when, for example, someone says, 'Where were you born?'

Another important type of memory is 'semantic'. This is the ability to remember what things mean. Knowing what the written word 'carrot' means or what a picture of a 'shirt' or 'toilet' indicates is very important for your basic ability to function in areas of life such as cooking, dressing or toileting.

3. Parietal lobes

The next brain area is the parietal lobes. This is the area responsible for your ability to find your way and not get lost, for example remembering where the freezer is located in the supermarket, or your car in the car park on the way out. It also helps put together the parts of a situation into a whole impression, for example combine all the sensory stimuli of a football match into 'an experience' of the match; or organise words into a pattern such as a sentence that conveys an idea. It also helps you recognise objects such as clothing or food. It helps us complete calculations.

4. Occipital lobes

Finally the occipital lobe, located at the back of your head, is where vision is processed. Here the brain interprets what you see (so you could say you do have eyes in the back of your head!). Vision can decrease for people who have brain impairment as the brain cells may be lost in the progress of the disease. Therefore brightness and even lighting, absence of glare, and contrasts between objects and their background become much more important for the person to function indoors.

Limbic system and emotion

The final major feature of the brain for our discussion of communication is the limbic system. This area is important for emotional experience, which is central to good communication. It consists of areas of all the lobes and surrounds the 'reptilian' or ancient area of our brain that we have in common with other vertebrates. The limbic system helps us put an 'emotional tag' on all our experiences. (We like it or don't like it. We feel attracted to some people and not others. We had a good time or we were afraid or angry.)

Emotions are a vital part of human living, as the feelings we have help us to appreciate, value and love the people, roles, activities and interactions we have with each other. Without them we have only survival reactions to guide our choices. Life would become mundane and lacking in colour without our emotions.

The limbic system helps us to sort out our preferences and make choices based on feelings, and often on memories of past experiences that may have

been pleasant and enjoyable or fearful and unpleasant. In trauma, this system helps protect us from extremely unpleasant emotional experiences by sometimes 'blocking off' feelings from the sensory parts of what we experienced in the past. For the person with dementia, past trauma can interfere with current day-to-day life because it can be confused with what is happening now. The limbic system recognises the feeling similar to what we experienced in the past, and memories may surface that have nothing to do with now, but a lot to do with what happened a long time ago, when it felt similar to how it feels right now.

> Tom fought in World War II in Borneo and was taken prisoner by the Japanese. He was interned in a camp for several years, during which time he experienced severe hardship and suffering, and witnessed atrocities that have stayed with him in memories. Now in his 80s, with dementia for the past few years, he sleeps poorly and wakes in a sweat at night with nightmares he can't explain. He becomes angry and blaming of staff when they ask him to do something like go to the toilet. He doesn't like feeling dominated or made to do things now. His body is thin and wasted, like it was when he was a prisoner. He feels afraid and believes he is back in the past.

Tom's mind and body are re-experiencing the wartime distress he endured, because both his mind and his body 'feel' as they did then.

The brain in daily functioning

Let us look now at several functions the brain helps us with through the day.

Memory

The brain is particularly good at helping us work out whether we have seen things before or not. If we see something new, our brain focuses on it and tries to check if it is important. For instance, if we are passing hundreds of cars on the way to work, our brain does not attend to each one. However, if one car hits our car we will remember the colour or make of the car because it has become important or significant for us. This tells us something about how we remember. If something is significant, it is easier to remember. Also, if it is emotionally important (like a car that hit us), we will remember it.

This is why a person with dementia may remember some things and not others. They will remember a staff member whom they like or dislike, but may not remember others towards whom they have no reaction or feeling.

The other important factor about memory is repetition. We learn by repeating things over and over, and so they become more easy to recall. This is important for people with dementia, who can continue to learn new information if we repeat it over again to them within the span of their decreasing working memory. You may be able to use this to assist the person with dementia to maintain their connection with past experiences. This is simply reminiscence and is incredibly valuable as a

means of helping the person stay in touch with their identity.

Language

Speaking our thoughts in a form that others can understand is a basic human ability and we often take it for granted. The complement of this ability is comprehension or understanding of what others say to us. This two-way ability is fundamental to human socialising and facilitates intimacy, problem-solving, diplomacy and the communication of everyday needs and wants.

In Alzheimer's disease it gradually becomes more difficult for the person to find the right words. As well as memory loss, the person can have increasing difficulty in participating in a conversation with the ease and fluency they may have once had.

> Dennis was a successful journalist who prided himself on his extensive vocabulary and command of the English language. When he began having difficulty finding the right word, and making mistakes he would never previously have made, he began to lose confidence and he stopped writing. He withdrew and stayed at home out of embarrassment that he could no longer think and speak with the once rich skill he had prided himself on.

The senses and the brain

The brain helps us understand what is happening in the world around us. It does this by taking in information

from all the senses – vision, hearing, touch, taste and smell. These channels of information flow into the brain with such speed that it has evolved a way to focus only on the information that is changing and concentrate on this, while processing the other information automatically, so that we don't have to concentrate on it. This ability frees up our brain to focus only on the parts of our life that are changing and not its routine, familiar aspects.

> Jean was a florist who knew flowers and plants so well that she could assemble a beautiful arrangement without having to spend much time on it. She did it automatically. But now that she has dementia she has trouble doing the everyday things she once found effortless, and when asked to do the once familiar and enjoyable task of arranging a vase of flowers, she becomes upset and overwhelmed.

Bodily sensations

Our bodies are connected to our brains by neurons that stimulate muscles and receive information from our skin and muscles. A hotplate on a stove can be hot to the touch, and our brains sense this and instruct our muscles to pull away to protect us from harm.

Our brains can read what is happening in our bodies too. The inner sensation you have when you are hungry, thirsty or need to go to the toilet alerts you to whatever action you need to take to solve the problem of how you feel in your body.

Mavis was very particular about her personal hygiene and always left plenty of time to go to the toilet wherever she travelled. She would plan trips around toilet stops and always 'went' before she left the house. Now that her brain is not reading her interior sensation of a full bladder, she is often agitated by the feeling and not able to work out what to do about it. Recently she had an accident or two that distressed her very much, with some embarrassment about making such a very personal mistake. She now gets anxious and refuses to go out on the bus or for walks in the morning.

Pain and the brain

The experience of pain is complex. The brain senses that a part of the body is in distress and interprets this sensation, causing the body to react to the sensation. For the person with dementia, recognising that a sensation is about pain may be difficult. They may be unaware they are in pain, or unable to problem-solve about the uncomfortable and distressing experience they are having. The idea that it is pain may not occur to them. As a result they may be unable to do anything helpful about it, either by telling someone else about it (which is what we do most of the time) to get help, or by doing something about it themselves. To act successfully about pain requires a complex sequence of thoughts that connect up, resulting in relief from the pain, and this may be too much to expect of a person with dementia.

For us the important issue here is to be able to recognise the signs of pain that a person with dementia may communicate using nonverbal 'language'. Remember

that behaviour is a language. Pain can be communicated through facial expression, posture, favouring a body part, vocalising (making noises or sounds), changes in behaviour or mood. Look for the signs and you may pick it up more quickly than the person with dementia, and be able to provide appropriate relief.

Tiredness

The person who lives with dementia may not be able to tell you they are tired and need to go to bed. As with other sensations, the experience of tiredness requires an ability to detect, understand and then act to address the problem. The person may not be able to do this successfully. What we see is the person becoming more agitated, irritable, restless or confused, perhaps. Each individual will be unique in their response to tiredness, so we need to get to know a person's way of acting when they are tired, and adopt an approach that helps them to remedy the problem without making them feel overwhelmed or dominated. This leads us into the person-centred way of communicating that helps us to focus our attention on the well-being of the person, and not just on the outcome of fulfilling tasks that have traditionally been seen as the purpose of caregiving.

Infections and the brain

In an older person an infection can cause the brain to malfunction more severely than in a younger person. Such infections might include urinary tract infections

(UTIs), chest and upper respiratory infections, or wounds that are not healing well.

The physical health of the people we care for is as important to us as carers as their emotional health. Therefore it is important to obtain medical diagnosis and treatment quickly and effectively for the person with dementia. Sometimes leaving it for several days before obtaining medical help can result in a poor outcome for the person, as their ability to fight infection can be lower than that of a younger person.

The brain and food

We know a good diet is vital for muscle strength and bone density. Your brain also relies on the nutrients that you consume in food and fluid to be able to do all the thinking, remembering, feeling, sensing and perceiving that you take for granted every day. A good diet is vital for a person living with dementia, just as it is for us all. Poor food equals poor brain function. Good food equals better brain function. So a balanced diet will enhance memory and thinking, help the person to be in a good mood and assist them to function to their full capacity. There is a great deal of knowledge available about balanced nutrition. If you are caring in the home and you are in doubt, consult a dietician or nutritionist to design for you and the person you care for a diet suitable for each of you in terms of age, physical condition and lifestyle.

Exercise 1.1

Brain functions in everyday life

1. What area of the brain is responsible for social behaviour?
2. What abilities are impaired early in the progress of Alzheimer's disease?
3. How does the limbic system help us function?
4. What areas of Tom's brain are involved in causing him to react strongly with emotion now? (See page 19.)
5. If you had problems with speech, what area(s) of the brain might be affected?
6. What parts of your brain do you use when you are getting dressed in the morning?
7. What areas of the brain are not working for Sarah? (See page 16.)
8. How does the limbic system help us react to the world around us?
9. Is the limbic system a reliable source of information about our current experience or does it confuse past and present?
10. How does your diet affect the way your brain functions?
11. How does your diet affect your mood?