**Breaking bad news to people with dementia**

Should you tell a person with dementia that someone close to them has died? The general rule of thumb is that if the person died many years ago it is preferable not to, because they knew the news, and their memory impairment has caused them to forget. Reminding them will be as though they are hearing it again for the first time. However, if the person recently died the following is relevant.

One of the first rules when caring for someone with dementia is not to add to their levels of stress. You might think that telling them bad news will be stressful for them. You might also think that there is little point in telling them. Won’t they just forget? Will they really understand?

The question of whether to break the news about a death usually arises when someone with dementia is living in a residential care home. Those people with dementia still living at home will be aware of the bad news because they will overhear phone calls, be party to the lead-up to death (visits to hospital, ambulance calling, etc.) or possibly even be there at the scene of death. In such cases never make the mistake of thinking that the person with dementia has not understood what has happened and can therefore be ignored or not involved in discussions about funeral arrangements and so on. Remember that in the slow deterioration within the brain the emotions remain until the end. The person with dementia may forget why they are sad but they will be aware that they feel sad and this will make them anxious. They may want to be with you constantly or they may start to pace around or be generally less settled than usual at the very time you may be hoping for some quiet reflection yourself.

The best thing to do in this situation is reassure the person with dementia and remind them occasionally of what has happened: ‘Yes, you feel sad because Joe has died. We all miss him.’

Try to keep the routine as much as usual and speak calmly and quietly. Do not ask difficult questions but involve them in the arrangements. For example, do not say (unless you feel they are able to still make decisions), ‘Do you think Vera would have liked “All things bright and beautiful” as one of the hymns at her funeral?’ But instead say, ‘We are going to sing “All things bright and beautiful” at Vera’s funeral. It was a hymn she always liked.’ It is also worth remembering that times of stress and difficulty may bring latent thoughts to the surface which should not be ignored. For example, the person with dementia may wonder who will look after them now if their main carer has died. They may ask you what seems like a trivial question ‘Who will drive Margaret to our house now?’ because, in this example, to them the main focus of their mind is that the person who has died used to bring their daughter to visit.

You could answer, ‘Margaret is going to drive herself here. She will be coming tomorrow.’ In this way you will be trying to answer the unspoken anxiety ‘Will Margaret be coming to see me any more?’ instead of the actual apparently unimportant question.

There is no reason to hide your own sadness if you are sad, although it may upset the person with dementia if they see you cry. In this case it may be best to just explain simply, ‘I’m feeling a bit sad about Joe dying.’ And leave it at that.

Try not to be upset if the person with dementia actually says something socially unacceptable: ‘It’s a good thing he died – I never liked him, you know.’ Although many people with dementia keep their social abilities for a long time and understand what is acceptable comment, others do not. People with frontal lobe dementia especially may be quite outspoken and say exactly what is on their mind. It is reasonable to say ‘Please don’t say that. It upsets me’ although this may not be effective, but it is probably a waste of time to show too much shock or try to reason on the grounds of ‘We don’t speak ill of the dead’. You could say ‘You will upset Margaret very much if you say that to her’ and this may work but, just in case, you may like to warn visitors ahead of their visit about possible upsetting comments which may be made.

It is very possible that the person with dementia may forget what has happened or may not be able to understand the finality of death. One man constantly said to the care workers in the home where he lived, ‘Yes, I understand that my wife is dead. You have told me before. But is she coming to see me today?’ Others may ask ‘Is Joe coming today?’ with monotonous regularity so that you want to scream at them to make them understand. The best thing to do is develop a ‘stuck record’ approach but add some reassurance: ‘No, Joe has died, remember. He won’t be coming to see us because he has died. But Margaret will be coming next week.’

A few weeks after our daughter died, I went to tell my ex-husband who was in a home some distance from where I lived. I took with me a picture of our daughter and told him, ‘Our daughter is dead.’ He looked at the picture and smiled and said, ‘Oh, but she has been here with me for a long time.’

You have to keep in mind that the person with dementia cannot control what they remember and what they forget. If they laugh at a joke, enjoy a television program or say they are looking forward to an outing they are not being insensitive. They are responding to what they remember at the time. It is best to just accept this behavior and certainly not to see it as disrespectful or a sign that they do not care about what has happened.

I remember that when my father-in-law died his daughter, Molly, came to stay with her mother for a few days. My mother-in-law had dementia. Molly confided in me one day that she thought her mother had never loved her father because she was still laughing at the comedy on television and didn’t seem to want to discuss the funeral. I was a bit surprised that Molly didn’t understand her mother’s condition.

It is definitely not a good idea to try to hide what has happened or to make arrangements in secret. The person with dementia will be aware of something going on and be more anxious, and more upset, if they think that you are keeping secrets from them. It is a very bad mistake to do this as you will be adding to the fears and anxieties which are never far away from someone with dementia. In addition you will probably not be able to keep up the pretense or someone else may ‘let the cat out of the bag’ with upsetting results.

My brother knew that Dan had dementia. Usually he was kind and gentle with him and often took him out to the pub or for fishing trips. However, at my sister Mary’s funeral things became very awkward. Dan kept asking when we were going to go home and began to be very loud and aggressive. My brother was already quite upset and he suddenly turned on Dan and shouted, ‘Why don’t you show some respect, you rotter? Don’t you care at all?’ The worst of it was that, unable to understand what he had done wrong, Dan burst out laughing. I don’t know whether he thought it was a joke or just didn’t know how to react. I had to take him home in a hurry. Afterwards my brother was mortified but I don’t think Dan remembered the incident at all.

There are many occasions when it is actually unkind to remind someone that their close relative is dead. Sometimes the person with dementia seems to be living in their own ‘shadow-world’ of the past. They may believe that they are still young and be convinced that their mother and father are still alive. If a wife or husband has died, the person with dementia may never really remember this and continue to cook meals for them, or tell you they are ‘down in the shed in the garden’ or in some other such place. If you respond by saying ‘No, Mum, he is dead’ it may cause real upset. It is as if the person with dementia is hearing it for the first time every time you say it. Imagine how you would feel if someone suddenly said that someone close to you has died when you had forgotten this and simply assumed that they were in another room somewhere. In circumstances like this it is best just to let the remark pass. After a few moments it is very likely that the person with dementia will recall the fact for themselves or they might be distracted by something else.

After my uncle died, my aunt seemed often to be unaware of this fact. She would explain away his absence by saying he had gone to the shops or was digging his allotment. One day she told me about a terrible dream she had had the night before in which a funeral car pulled up at the door and she was driven to a funeral service and my uncle was cremated. At the end of this account she suddenly shivered and said, ‘Thank goodness it was only a dream.’ I didn’t know how to respond.

If the person with dementia is living in a residential home when someone close to them dies, it may be tempting to keep them in ignorance of the fact ‘because it might upset them unnecessarily’. It is understandable that this notion may be considered. If the person with dementia is settled in the home and seems happy it might seem cruel to disturb that equilibrium, especially if the news can be kept from them successfully. This is the important point. If the person who has died was a regular visitor it may be impossible to keep the death a secret. Even if the person with dementia appears not to recognize visitors, or is unable to name them, they probably know they are familiar people. They may well experience pleasure at the visit and feel better afterwards. Even if they are unable to actually ask why the visitor no longer comes, they may sense that something is wrong. The loss of the ability to put feelings into words does not necessarily indicate the loss of feeling. One elderly man in the care home where I worked was frequently visited by his daughter and her children – his grandchildren. When his grand-daughter" "died in a car accident he was informed. His daughter continued to visit with her other child and it seemed as if this man didn’t register any change. But one day, a couple of months after the death, another resident had a visit from a small girl relative and this man became very upset, shouting incoherently and crying and upsetting the little girl. We thought afterwards that he was just expressing his feelings about the death of his grandchild – there was no other way he could tell us how he was feeling.

It is probably best in such cases to tell the truth. Of course there will be upset feelings and sadness, but sadness is normal and appropriate after a death. In such cases be sure to take the staff of the home into your confidence and warn them when you are going to break the news. They can then be prepared for any unusual behavior or even take the time to help the person with dementia express their grief in the best way for them. You can tell the staff that you will be happy for them to talk about the loss if the person with dementia appears to want that.

If someone is very severely affected with dementia and no longer responds to visitors or seems to recognize them, it may be better to conceal the truth. However, it is important if any concealment takes place to make sure that there is no possibility of any chance remarks giving this secret away. It is also a good idea to tell the care home staff what you are planning and make sure that they too understand what should not be spoken of. It is easy for inexperienced staff to believe that an unresponsive person doesn’t take in what they are gossiping about whilst making the bed!

One lady with dementia living in a care home began asking the new manager where her husband was. The new manager had been told that the husband had died many years before but wasn’t sure whether she should mention this or not. She prevaricated, promising to check the records and find out where he was, hoping the resident would forget her question. But the questions continued. Eventually she had to say, ‘I’m very sorry, Linda, but your husband died several years ago.’ The lady replied, ‘Yes, they told me that, but I thought I’d check to see if you knew.’