

COMMENTARY

Communicating with people with dementia

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Summary. It can be very difficult to communicate with people with dementia. Each case requires its own unique handling. Not every scenario is covered, as many times your own judgment is what will work, best according to the circumstances. These can change from dawn to evening and from day to day. Never assume things will be the way they were the last time you communicated. Be on your guard. Be adaptable. The article will help get you started to think of your own ways to communicate.

Key words: ethics, physician-patient relationship, mental health.

INTRODUCTION

Alzheimer Europe is a non-governmental organization aimed at promoting co-ordination and co-operation between Alzheimer organizations throughout Europe. Alzheimer Europe divulges knowledge and is a source of information on all aspects of dementia.

In 2011 Alzheimer Europe set up a working group which addresses the most relevant ethical issues in dementia research. The working group will publish recommendations and guidelines. The working group is composed of experts from different European countries. A valuable contribution is given by James McKillop, who participates in the working group as a member.

James McKillop is founding member of the Scottish Dementia Working Group (SDWG). SDWG is an independent group run by people with dementia: membership is open to people that, as James, live with dementia. The purpose of the group is to campaign to improve services for people with dementia and to improve attitudes towards these persons. James McKillop is well known for his continued and tireless campaigning to highlight the need to support people with dementia and their carers. On 6 July 2011 he has been awarded a Member of the British Empire (MBE) from the Queen in recognition of his work to promote the rights of people with dementia and to raise awareness of the disease. James McKillop has taken part in several research studies and has reported his experiences in prestigious international conferences and events.

The following writing by James McKillop gives a vital perspective on a patient-centered communication in dementia care and research. It is a lively lesson on the need to see the person in the patient.

COMMUNICATING WITH PEOPLE WITH DEMENTIA

You need to find the right place, at the right time in the right surroundings.

Consider yourself.

Do you take in information or make your thoughts clear, when conditions are not ideal, for example if your bladder is bursting, you were up during the night with a sick child, or you have worked all morning without a break?

It would be very difficult indeed.

So when it comes to communicating with people with dementia (PWD) who are battling a disorientating brain illness, it can be a nightmare, unless you make it as painless and simple as possible.

I believe that apart from the very severe stages, PWD can make a choice, be it an oral answer, a nod or shake of the head, or perhaps moving a part of their body such as a finger. The trick is to get to know how they best communicate and go down that line.

Find the right place.

If someone transported you to a busy office or to a strange room, would you not be distracted? Unwanted stimulation from their surroundings would maybe detract from the value of the meeting. You have disrupted their routine and a

routine is important to PWD. Perhaps meeting in their own house or own room in a care home, would be best, so they can concentrate on what you are saying.

As far as possible, make sure they are comfortable. Have they been to the toilet recently or have they had something to drink? Is there some liquid to sip as the meeting goes on? Are they still in their nightwear and you arrived too early? Are their clothes appropriate for the day and look comfy? Are they sweating, itching or cold looking? Some people while cold, do not feel or mention it? Is the room temperature at either extreme? If time passes and they are now in direct sunshine are they getting roasted? Are they sitting in a draught, or is the room stuffy and stifling? Are they sitting in a hard backed chair while they offered you their favourite chair? It's best to check. Is their chair and yours are at right angles, it is vital you talk face to face. Ask if you can move your chair. Don't approach from behind and only talk when they can see you clearly. If you are greeted at the door and follow them into a room, do not talk until you are both seated and at the same eye level.

Tell them your name and perhaps wear a large name badge to remind them who you are and explain why you are visiting them. Your demeanour will count for a lot and calm and reassure them you mean no harm. An older person at home with a lot of life experience, may think you are there to put them in a care home, as they will have seen it happen.

Lighting is very important for people as they get older. Try and ensure your back is not facing a bright window, otherwise your face will be in darkness. People like to see people's emotions as their lips move, to read what is unsaid. If the room is not bright, ask to put the light on, so they can see you.

It may not be your job for their health and safety but if you are, consider that the new types of low energy bulbs may not shed enough light for them to see to move around safely, or perform other tasks. Do they need extra lights around the room to increase the overall illumination?

Face the person and speak clearly. The tone and volume of your voice is important. Many people who are older, have hearing difficulties. Do not talk too quietly, screech at them or flap your arms about. Find the level at which the person can hear you clearly and maintain that level.

The pace is equally important. Do not talk too fast, nor talk slow like this;

Good...morning...how...are...you...today. It is demeaning.

If the person is deaf and you are working with a signer, still face the person and talk at a pace the signer can follow. Have pauses be-

tween sentences for both the signer and the person to catch up, as it is an exhausting procedure.

Don't ask two questions or make two or more points in the one sentence.

If you start to speak and they also start to speak, always give way. It is very easy for the person to forget what is on their mind and if there is even a small delay, they may well not remember what they wanted to say. You may be on a tight schedule, but give them time to reflect and think.

While it may be beyond your control, look to see if extraneous noise from inside or outside, can be reduced or eliminated. This can be TV, radio, other people in the house or home or traffic noise and road works from outside.

If they wear glasses, suggest they put them on, which helps them follow you.

Similarly if they have a hearing aid. I visit an old lady with the Alzheimer's type of dementia every night, who will just not wear her aid and I have to speak very loudly and repeat myself, and, being honest, this wears me out.

Don't pretend to understand/hear something said if you don't. They may have said that the cat died and you smile encouragingly. Try another approach to see if that helps, or just be honest and ask them to repeat themselves, as you didn't pick up their point.

The right time has its place. Many people take medication for all sorts of conditions and these may still be in their system in the morning or some hours later. Do your homework and find out when the person is at their best, say morning, noon or afternoon. If possible try and not have the interview coming into a meal time or ending just before it. Hunger may prove to be a distraction. Use your ears. Are they shuffling their feet, or is their tummy rumbling? Do they lick their lips?

So what can you do. Understand people are reticent to open up to a stranger. Do you yourself, tell a stranger personal things about yourself? It is quite difficult. You may need several meetings to gain their trust and understand how they operate. We all have our own ways. It is up to you to adapt.

PWD may not realize their shortcomings and think everything is hunky-dory. They may claim to be able to perform functions, when in fact they have lost the ability. What proud person will admit to their failings, say for example when it comes to personal hygiene or looking after themselves, when they may have brought up a family during the hardships of the war.

Read between the lines. You may sense that what is being said does not match up with what you observe or hear being said. Tread carefully to get to the truth. For example they may say they clean the house daily but dust is

an inch thick on the mantle-piece, and the bin is overflowing.

Treat them as you would a person with or without a disability. That is, as a person, a human being, with a rich life behind them. A person who survived hard times, and who may have gone through trials you could not imagine.

Jolt their memory. Important facts may not be remembered immediately.

Ask a direct question to get a positive reply. For example in my mother's care home they would ask her if she wanted a cup of tea, to which she would reply "yes", as she was thirsty. However if they said do you want tea or coffee, she would have said coffee.

Be aware the PWD can tell convincing lies. They do not do so deliberately, as what they say is the truth to them, as they remember it, at the time. They may easily contradict themselves a little later, as that is what they are convinced of, at that later point in time.

Don't flog them to death. Concentration can be limited so build in breaks. A cup of tea, a chat about photographs in the room, books, pets, grandchildren etc. Set yourself a limit to stay, say an hour and continue another day if necessary.

It might be a serious matter you are discussing, so smiles may not be appropriate. However do not sit with a deadpan expression. Show some animation and, if necessary, show some empathy.

Don't finish sentences and be patient. Don't presume to know what they are about to say. Understand they may ask the same question frequently or repeat themselves ad infinitum. Never say you have just/already said that. Look interested and treat it as a fresh bit of info.

Consider all communication tools which are available. For example there is an excellent system called Talking Mats and you can learn more about this from Joan Murphy at (www.talking-mats.com). I personally have used Talking Mats with my wife and while it was not the purpose of the exercise, it was clear I have problems moving about in the house or when outside. I hadn't realized this before and this brought it home. I am now going to the doctor.

The Mats, for once, gave me the chance, to have the last word.

It can be frustrating dealing with someone with dementia, and do not feel you are somehow to blame. Never let it show as they will pick it up and the rapport can be lost. Grit your teeth, take a deep breath and carry on. Remember someone with a communication problem, can also get frustrated if their views are not understood or, if their speech comes out muddled.

Read their body language and non verbal messages. If they are giving out distress signals or seem not to be understand you, it may be

something is troubling them such as needing the toilet, or they simply cannot hear you clearly. They can be become distracted, anxious or discombobulated. Remain alert at all times.

Communication can take place through touch. You may touch/hold a person's hand or arm and convey the warmth of your personality and show understanding, sympathy and empathy. Most will appreciate it. I do. It may have been some time since anyone showed some feeling. Some will absolutely love it, but the odd person may dislike it and recoil from you. So be aware a potential problem can arise, which may ruin the relationship.

Don't give them a pat on the head, as has happened to me.

If they are a wheelchair user and you need to move it to aid communication, ask permission to move it and explain why. It is a part of them by extension.

I can offer no advice. You have to read and judge the situation yourself.

While you should give the PWD their place, truthfully it is helpful to have someone who knows them well present, to fill in the gaps. If not, try and double check with other sources. But do not talk over their head or around them if someone is present. Always look at, talk and respond to them directly. Don't invade their space but remain in eye contact.

Hospitals. I have been both an in-patient and an out-patient and while the end result was successful, the process did not go well. There are problems peculiar to hospitals such as times to see patients when so much goes on all around them. The noise and distractions are unhelpful. You just can't re-arrange the ward to suit you. If you can take the person away, so much the better. But this is not always possible. One person's best time may be when someone is in dire need of nursing and they take priority. How can you look someone in the eye when the bed is high and the chairs are low. The nurse or patient may have to twist their body or neck to see properly, whether sitting on a chair or on the bed. The last thing you want is a health and safety issue. Towering over someone who is lying or sitting up in bed is not the best position to communicate. Is there any privacy as beds are nearby? Drawing screens round you doesn't help as every word can be heard by those nearby, especially if you have to raise your voice to overcome hearing problems and ward noise. I know some nurses will try and use a room such as a day/tv room but may need to ask another patient for a bit of privacy.

There is no problem in side rooms/staff rooms where one is alone.

In side rooms with a small number of beds, the nurse may need to ask the others to turn off TVs or for a bit of quiet for a moment.

I see the problems hospital staff have, but can offer no solution to cover all situations. You have to do your best in the circumstances at the time and use your initiative. Never feel disheartened. You can only work with what is there. This is a time when I feel a soothing touch would be most welcomed. We appreciate you always do your best for us.

Telephone communication. This can be trying for both parties and I think the best advice is to use common sense. People in the early to middle stages may be able to hold a two way conversation, but still struggle at bits. I think you should offer to meet them at a place and time convenient to them and emphasise that they can have someone they trust with them. If the problem cannot wait, deal with it and send them a letter summarising the position and repeat the offer to visit. Do not cajole or coax, suggest a face to face.

If you have been in telephone conversation with them before recently, you should have an idea how to proceed. If you have talked to them some time ago, say six months, and it went well, remember there may have been a deterioration in their condition, so proceed cautiously, to test the lie of the land.

If you do arrange to meet up, send a letter for their fridge. Phone the day before to remind them, and again on the morning in question. Both to remind them, and to specifically ask if they are still able to have a meeting, as circumstances may have changed overnight and they are having a bad day.

If you detest cigarette smoke and find they smoke while you are there, you have a right to work in a smoke free zone. On the other

hand it is their home and they have a right to do as they want. I feel you would be justified in pointing out you are allergic to smoke and you will excuse yourself until they have finished. You could ask in a nice way to use the toilet and take your time, or ask to open a window as you need a breath of fresh air.

There is no easy solution and you will have to do what makes you comfortable.

I believe there can be particular problems when a person with dementia attends a doctor's or a dentist's. If they are in the middle to late stages, how can they communicate, where a pain is? How can you do a procedure which involves pain or discomfort and expect them to understand you are trying to help.

I need more thought on this one. It helps not to leave sharp instruments in easy reach. They may grab/touch/handle them and get hurt.

Remember, this quote by GB Shaw. "The single biggest problem with communication is the illusion that it has taken place".

N.B. Abuse: mental, physical, financial or sexual. This may not be the purposes of your visit and outside your remit or experience, but, if someone communicates that they are being abused, in their own home, in hospital or in a care home, contact the proper authorities. Remember abuse can come from strangers, staff, a fellow patient or someone asking about something like an accident and trying to get them to sign something like a disclaimer. Families can be a source of abuse, and ask you to sign papers which benefit them but not the person.

Finally I believe common sense will win the day.