

Talking Point chat room 13 October
Confusion, resentment, refusal – dealing with challenging behaviour

SerenaS	Hi everyone, welcome to the chat room today. The topic is confusion, resentment, refusal - dealing with challenging behaviour. If you'd like to ask a question, post an experience or just say hello, please do.
jaymor	Hello Serena
pipb	How do you deal with it when a sufferer with mixed dementia just refuses to do what is asked of her by a carer - in this instance I mean refusing to have a shower, take tablets, etc.
SerenaS	Hello jaymor and pipb :)
SerenaS	Thanks for your question pipb - do you think that the person is able to what they're being asked to do?
pipb	Yes, definitely, but she thinks she's already doing these things perfectly well, every day, but isn't. My mum hardly ever showers or washes her hair any more, and has started pretending to take her tablets while the carer is there, and hiding them - we find them underneath things all over the house
Oxy	Tablets -crush and conceal in yogurt/marmalade, not good for coated/prolonged release. Strip wash? Dry shampoo?
pipb	Hi Oxy - she says she has a strip wash every day as well, but doubt it as she is starting to smell a bit. Carer's won't do the crushing tablets in stuff
Oxy	I think, from reading, many have fear of shower. C loves a bath when we go for one but shower refused.
jaymor	Pipb is there something that would be enjoyable for her after the shower. So along the lines, your shower is ready and when you are finished we can..... Bit like the carrot and stick.
pipb	She also won't use a dry shampoo because as far as she is concerned she is washing her hair! But she has scabs all over her head which she is constantly picking at, and I'm worried that she'll infect them. I know she isn't washing her hair as the bottle of Head and Shoulders shampoo I got her last January is still full. Have tried persuading her to have it washed and dried/set at the hairdresser's at the Age UK centre she goes to on a Wednesday, but she says it's not necessary as she can do
Oxy	Unfortunately they always say that Pipb. I got round the refusal to strip wash. But before she'd say shed done it and saw no knickers in basket so knew they hadn't been changed. Meds-would it work for you if you put tabs in jam /yogurt in a little plastic pot. Carer thing so hard with meds e.g. they don't do slightest blood sampling for diabetes even.
Violet54	Hello everyone, I find it fascinating that dementia seems to cause the same symptoms in everyone. My mother has all of the difficult behaviours, refusing to wash being the most challenging. Her carers are managing to shower her just once a week at the moment, we've tried telling her she has a doctor's appointment, visitors are coming, every excuse we can think of. Now the only thing that seems to work is to tell her that her mother would be ashamed of her if she knew!
Lindy50	Oh pipb, I have the same problems with mum. She just won't have any help and truly believes she does everything for herself. The smell is now noticeable, as are the dirty clothes. I just don't know when it will all end...
CollegeGirl	Hello everyone - I was wondering if anyone has any tips to help dad get mam into the car? About half the time, she just refuses. It doesn't seem to be a physical problem, just awkwardness but it can get very aggressive.

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Oxy	Specific problem with car, or are all requests 50 per cent responded to?
SerenaS	Hello CollegeGirl - that sounds like a difficult situation. Sometimes there can be a number of reasons why a person may not do something - I'm wondering if she feels afraid, is apprehensive about where she is going or struggles to get into the seat?
CollegeGirl	Oxy - no, things are very hit and miss generally. Serena - no problem with seat as yet, more refusal to even get in. You might well be right about apprehension or fear. How do we deal with that?
CollegeGirl	Oxy - sorry, yes she does refuse to do other things too, often, but this particular problem is difficult because it's more public. People can be watching and wondering what's going on, in car parks and such like. Makes it really difficult to deal with as it's also embarrassing.
Oxy	Oh, I feel sorry for you, CG, I get embarrassed too when we have whimpering and croc tears that sound like real ones when doing simple actions that are difficult as getting into a wheelchair.
nitram	I had the car problem. One solution was patience, walk away from the car and return, approach car from different direction, you have to learn to ignore onlookers, it sometimes took around 20 minutes, and journeys to the day centre were solved by using their transport with hoist.
SerenaS	Some great suggestions - thanks everyone :) CollegeGirl - you'd mentioned dealing with fear. Sometimes people recommend acknowledging feelings, some say that it's worth trying again later, others say that distraction and being careful not to show irritation can help.
CollegeGirl	Thanks for all the suggestions everyone, I'll pass them on to dad.
CollegeGirl	Oh dear, Sarah - how did your friend react?
creativesarah	when I was at my sisters she said in front of my friend who took me to see her " are you allergic to water , or are baths and showers rationed where you live"
creativesarah	My friend and I can laugh about it now
creativesarah	The reason I didn't want to bath at her house was she had a freestanding roll top bath and I thought one of the legs didn't look secure and as for the shower she gave such detailed instructions about how to squeegee it down I was frightened I wouldn't do it right. My friend was totally humiliated on my behalf
Lindy50	I'm glad you can laugh about it Sarah....I'm not sure I'd be so forgiving!
CollegeGirl	Piph - i bought a bottle of no rinse shampoo off eBay. I used to get mam to sit on a kitchen chair and then I'd put a towel round her neck and just get on with it. She would moan but it got the job done. Of course my mam is way past this as a possibility now, but perhaps this method might work for your mum at the moment?
Oxy	Hair washing I haven't cracked. After doing it always says I won't leave it so long again. BUT then won't because it was only done yesterday(memory)
Lindy50	Dry shampoo is definitely something I'll try. If you don't try you never know.
piph	The reason I'm asking is that SS involved now and a new care plan being put in place - they are supposed to ensure she showers twice a week, and washes her hair at least once, and I just know she's going to refuse.

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piph	I was just trying to come up with some way they could persuade her. I was thinking of making a daily chart for mum to have so she knows what is required each day - perhaps if she sees it written down and knows it's what I've arranged then she might be more compliant - any thoughts?
Lindy50	Might help piph....increasingly, mum will say 'is it on the calendar?', and if it is, she will be more inclined to think maybe she must have agreed to whatever it was!
CollegeGirl	Piph - dad had this problem when a carer first started to come to shower mam. Eventually they tried two carers coming together, and between them they eventually managed it. Now, mam has a shower and her hair washed twice a week which is acceptable, and the nasty smell has gone. It took a long time, patience and perseverance, and a lot of aggro, but two carers worked for us.
piph	Ha, that phrase "I did it yesterday" has become my Mum's mantra!!!!
piph	Thanks everyone - I'll certainly try all your suggestions, but think I'll do the chart first, hopefully that will help her understand! We have terrific arguments about why she needs the carers to come in, and she's not far gone enough to just go along with her.
nitram	Hair washing solved for a while by kneeling at side of bath and using hand held shower, main problem was recovering from the kneeling position. Doing it in the wet room as part of shower was a no-no, I always went in the wet room with my wife.
creativesarah	Wondered if the person being cared for had a childhood routine e.g. we always had our bath on Sunday nights while sing something simple was on perhaps you could reconstruct the event we had toast and dripping after!!
nitram	That assumes they know it's Sunday!
CollegeGirl	It wouldn't actually have to be Sunday!
Lindy50	That's a brilliant idea Sarah...well; it would be for me, anyway. Not sure about mum, I don't think baths were a pleasure when she was young ;)
creativesarah	true but i just wondered if a reminiscence of the past would trigger a secure feeling and it may never have occurred to her for the rest of her life that you needed to bath more than once a week!
creativesarah	You can probably get music like sing something simple!
CollegeGirl	The chart is definitely worth a try, piph, you have nothing to lose and sometimes the simple approach is the best one. Good luck.
Oxy	Chart is lovely idea if they can see! Always wants to see nice hair after washing/ cutting but can't see it which is no aid
SerenaS	Hello sarah, Oxy and nitram - thanks for your suggestions :)
CollegeGirl	Perhaps make a game of it, with 'before' and 'after' photos of her makeover?
Lindy50	It's a good idea, Sarah...it might go along with the chart idea actually. Worth a try, anywayand the more pleasant I can make things, the better :)
creativesarah	you can get a cd on amazon just had a look
SerenaS	If you've just popped into the chat room, today's session is about dealing with challenging behaviour, like confusion, resentment and refusal. Please do ask questions or share your experiences.

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nitram	Another problem which just required patience and time to solve was what I called 'sticky feet' - feet just apparently glued to the floor. I used to tell carers that if I could find the formula for the adhesive I'd sell it to B&Q and make a fortune!
Oxy	Best to choose a 'good day' when they are energetic. Somehow easiest when appt due where they may have to fiddle in hair area!!
Oxy	I think perseverance eventually gets results. Hair washing is VERY difficult for us in all honesty. We play a game going to bathroom sometimes where I hold both hands and trot along slowly ahead. Usually giggling in process!
Oxy	Routine important.
nitram	I gave up on routine. If not going well, try again another time/day.
Oxy	Routine of process-not time at all
nitram	Routine of process? Not sure about that, I tended to adapt to what was happening at the moment. My wife was non verbalising from an early stage so interpretation and adaption became second nature.
CollegeGirl	I need to go now - bye all, thanks for your help :)
SerenaS	Hi everyone, I'll be closing the chat room shortly. Thanks for taking part in today's session.

Thanks for reading the transcript from our chat room session on 13 October.

Some helpful resources on this topic are listed below:

Dementia and aggressive behaviour, an Alzheimer's Society factsheet:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=96

Unusual behaviour, an Alzheimer's Society factsheet:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=159

Washing and bathing, an Alzheimer's Society factsheet:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=155

NHS choices guide to dealing with challenging behaviour:

<http://www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/Challenging-behaviour.aspx>

Alzheimer's Society National Dementia Helpline - 0300 222 11 22; further details about the service here:

<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200365>

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If you have questions about our chat room, please contact us by emailing

talkingpoint@alzheimers.org.uk

You can view the chat room here: <http://forum.alzheimers.org.uk/chatroom.php>