

## UK WANDERING NETWORK

### Notes from a structured facilitated discussion group

Note: Each bullet point or sentence comes from a different group member. Group members generally made several contributions over the course of the discussion. 'Pass' means the member had nothing to say at that point.

- I would start with the question: How do we educate society about older people with dementia who wander?
- In this 1<sup>st</sup> round of our discussion I ask what the question means to me (proposed by the previous participant)
- For me this makes me think about the use of language we in [names the Nursing Home] use when talking to others.
- Its about using appropriate terminology like 'empathy'.
- Talk to public, Get feedback. Look at how they react. Get information from them.
- Do what Tony Blair did - A "Big Conversation" but on wandering
- When do we get the time to educate society? But I think we can educate families.
- How do we educate families then? - Communicating, Discussions, Meetings e.g. Relative Groups?
- Pass
- In my Care Home Setting - we work on admission and families
- We hear a lot of stuff about Specialised Services but what does that mean.
- A lot of care takes place in general settings not specialised settings.
- Use of language is important. We can start the process off: stop using "Specialised"!

- Basic rights of people with dementia - where are they/. Society shuts people in institutions People with dementia are not children -
- They are people with MH problems. But they do have a right to wander.
- Bring it right back to basics. Perception of dementia in our society is what it's about.
- Its chemical changes..... it's a neurological condition not a MH one, There needs to be challenge to the horrible socialisation we've been through. Overall, for me, the universal thing is to challenge.
- Exciting questions - but daunting. Ageism is evident even amongst older people. Its more about pulling out ways of changing attitudes.
- Older people are looked at as a whole
- Will I think we will have to deal in a better way with an ageing population.
- There is no answer to this wandering problem
- I say it should start with educating children - they will be decision makers in 20 years.
- It's a long term thing of course - it won't happen overnight.
- [example of a story to illustrate children have open attitudes to dementia]
- Excentricity can still mean living in the community and needing to be 'Locked Up'
- I also think educate Children and professionals (not just health but local authority and police etc)
- Local people like Café Owner's are important too - But we must keep rights to privacy and confidentiality in mind.
- I'm thinking, does it need a National Campaign.

- I ask 'What can I do?'
- I don't think we spend enough time with relatives asking them about their fears.
- It doesn't concern people unless it's in their family.
- It's difficult to get over barriers in family members.
- Maybe we need to have a package in place to use with families about how to address their fears.
- *Facilitator: There are both practical and bigger points being made here.*
  - *Right to wander stood out.*
  - *Re-socialisation about what's 'normal'*
  - *Practical things to address care.*
  - *Is wandering a right? If it is, what challenges does it raise?*
- We have a democratic society - Each individual has right to wander. Only time the individual has intervention is if they are danger to self or others.
- We're embarrassed by unusual behaviour (eg PwD) - we are just getting used to dementia in general) We see PwD as embarrassing and then the behaviours are too.
- It's the labels we attach - emotive words - It creates an image of danger. Terminology creates views society has. - Educate kids - Bring them into Care Homes.
- Yes, I feel they have a right to wander but how far does it go if it interferes with others.
- At moment we encourage staff to give explanations to other residents in our home. We don't stop the wandering.
- If all residents have freedom to do what they want we can't explain that to everyone.

- It can create a dilemma between residents in an enclosed environment.
- Is this because we don't recognise wandering as a need?
- Practical tactics can be used in those situations.
- Paint, change colours, beaded curtains over doorways.
- If someone wanders into someone's room what are they looking for?
- That's fine to let it happen, unless you have two clients who both don't understand.
- The discussion is coming back to care environment. This is fairly easy to change, is wandering in the community harder.
- How many of us are involved in community care?
- I see the person's home is part of the Community - wherever it is.
- In my Home - residents go out every day (age ranges 50 - 100) Involved in the Community - Just happen to live in a Care Home.
  - *Facilitator: Can we say any more about right to wander.*
- If residents go out and wander, staff allow them to wander off.
- We do too. If staff are anxious - we bring them back. I believe people see PwD as disruptive - Society needs to be educated about what children and older people should be able to do.
- We judge behaviour differently in different places.
- Need to know client well, and the environment well.
- It's about see wandering in a broader way.
- The environment at home can be changed. Environment outside is harder to change.

- If I sent resident into hospital and environment was stressing them I would send a carer in to be with them.
- Society's view + professionals as well have certain views Dementia = Incontinence Immobility etc.
- We have an issue with some clients not getting Communion because they don't understand what's happening so the priest won't do it. Some clients are not able to get to the Chapel. Spoke to Priest. His attitude was the Home was too noisy for communion. Clients don't always relate to Mass in the same way as before. I am challenged it -and am writing to a Senior Member of Church at the moment.
- It's odd people hold on to those basic beliefs.
  - *Facilitator: Because.....*
- Maybe he's right - it's not same as going to Church. There is visual stimulation in Church.
- The environment is different to what he's used to in Church but if the person is asked they say they want Communion.
- (What if you took a group to Church?) And they wandered. What would happen?
- A lot of Tutting - and probably they'd be put out.
- It would no different for a child.
- If it was a child you can jolly them along, with an adult others feel Intimidating.
- A lot of relatives say that
- This moves into the "wanting to protect them" from others and judgements. Then the way to deal with this is to withdraw.
- So..... the first job is to educate Relatives - "move them away from They are doing this to annoy me"

- Sometimes relatives are in denial
- In relatives meetings - they do communicate and talk about their fears.
- I think I earn more from other relatives sometimes more than professionals.
- "Wanderer's" come in to the relatives group and this is discussed.
- Story given about an Older Couple in a local Café, The woman wanders - she goes to the bar lifts the drink, The man is embarrassed.....The manager and barman dealt with this by asking customers to pick up their drinks until she goes and sits down.
- So he got others to change their behaviour.
- It seems small stuff - but there was no big explanations about Dementia.
  - *Facilitator: Protection from attitudes of others is emerging that's why Asylums were created (If we think of asylums as a place of Refuge how do we create place of refuge in society for PwD who wanders?)*
- Opportunity for another Job for me with café owners as they will need to call on someone for advice.
- Things are changing here slowly. In the US people with disability go anywhere.
- An example was shared about two people with Learning Disabilities and Dementia and Carers. One wandered off -and some of the public used terrible Language about them.
- We have a duty to explain to others.
- There is not going to be a label saying Dementia / Wandering.
- People need to accept it.
- Should we have Directory of Dementia Friendly Places?

- Would that be fair?
- You don't see Alzheimer's over the door because of the stigma.
- We must stop taking people out on 'School Trips' and take out on a one to one.
- When people are out on trips, carers wear uniforms and residents are paraded around. They stand out to start with
- Wearing Uniform in public is demeaning to PWD.
- I want to go back to Acute Care - Society had better acceptance of wandering we could have standards for wandering. 11 patients out of 18 are wandering. They have no where to go.
- Our MH Unit had a garden that was foolproof. And an activity room. There is a gap between specialist provider and Acute Hospital. It's a "disgrace"
- Change Community Spirit - To see it as normal.
- How much inbuilt defence do we have about Wandering?
- I think it's about having resources and bringing in Nurses to 'Special' the PwD who wanders.
- Education within ourselves is happening.
- We are part of it. Even using the term word Dementia. I use word Rementia now. Onus is on me to change my language.
- Loose the label
- Describe the Symptom.
- We're learning but we are surrounded by older people who see Care Homes as being put away.
- This is still not educating older people who deal with Dementia.

- I run an Education Groups for Carer's. Plenty of Carers come saying Doctor didn't explain it to them.
- Don't you feel younger people are being brought up with it.
- I challenge this - It's not on the agenda at school.
- Progress is always slow - Lots of progress has been made over last 20 years.
- Finance is any issue - there are a lot of dynamic Nurses, but they are not the guardian of the purse - both are at loggerheads.
- Good point re: Finances - Government is encouraging families to care more
- Money is not there for Care of Older People in the Future.
- If less families to care, what will Health Service care role be?
- Needs to be a big shift to Health Promotion - Risk Factors there - make the number one link to dementia
- As a society scared of the word 'Dementia' educate the community about Dementia (Not Medical view of it but how it effects people) Opening doors of Care Homes - let People Out and the Community In.
- Our obsession with risk is putting autonomy at risk)
- Children just see PWD as a person.
- We get wrapped up with Health and Safety Legislation.

## **SUMMARY**

One point by each participant:

- Wandering is very big issue.
- It's like AIDS education.



- Every individual makes a difference.
- Just touched on it.
- Keep thinking about what each individual can do to involve the family
- I feel uncomfortable doing what I'm doing now - due to politics of my organisation. I am going to go back and talk about it.
- Educate society - sounds easy but its not. Need to ask what am I doing - What impact does it have?
- Made me question my practice on education and the pre-assessment side.
- More education.
- It's about willingness to help.
- Think about what resources are in Community/Local Area and use them.
- Covered a wide spectrum on wandering. We've been educating each other today.
- Open dialogue helps.
- Technology as a springboard for further dialogue.
- Things can be challenged. Bad practice is not set in stone.
- It's what I do.
- Stop saying why can't we, Why shouldn't we .....and do it