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Person-Centred Advocacy for People with Dementia – a Personal Account

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Part Two

Introduction and Background

This paper is the second part of an article describing the experience of offering person-centred advocacy to older people who have dementia. Part one described the process involved in conducting an advocacy consultation in a residential home over a six month period and the themes that emerged from interviews with the residents. This final part will expand on the ethical issues alluded to in part one and will raise some questions arising from the work.
As stated previously, this is a personal account based on the experiences and thoughts of the main author, which is why it is presented mostly in the first person.
For a full picture of the background to this piece, it is advisable to read the first part of this article which sets the work in context.

Ethical Considerations

My experience of offering advocacy to residents with dementia led me to reflect on four ethical areas:

- What constitutes consent?
- The relationship between the ability to give consent and the possibility of inclusion or exclusion
- Confidentiality/sharing information: the right to know versus the ability to cope
- The use of touch to assist communication

What Constitutes Consent?

'People who lack capacity to consent or refuse a particular ………option may still express willingness or unwillingness to co-operate with what is being offered' (Dept. of Health: Seeking Consent p.10)

I feel strongly that the issue of what represents consent must be viewed more flexibly when dealing with people with dementia. If a person is unable, through cognitive impairment, to give consent as it is normally recognised, I believe that it is important to look for other signs that might reasonably be interpreted as agreement to be represented. Therefore, as a practical step, I assumed consent to have been given if a resident with dementia was willing to sit alone with me and speak freely about the circumstances of their life. Where their level of understanding allowed I asked: 'May I say this on your behalf?' I also noted statements that were repeated, or said with particular vehemence, where possible repeating these back to the resident to allow the possibility of confirmation.

An example of this is an Afro-Caribbean client who tended to relate all my questions to the time immediately prior to her last stroke, but who once, with great feeling, described the day centre for Afro-Caribbean people she attended as a 'lifeline'.

Conversely I feel that a sustained unwillingness or inability to engage cannot reasonably be interpreted as consent, however much the person being approached might appear to need help.

Another important point relating to consent in the specific context in which I was working, is that information given at the time of the initial consultation might have become obsolete eighteen months hence, ostensibly the time when practical changes would be implemented:

'Seeking consent is part of a respectful relationship with an older person and should usually be seen as a process, not a one-off event.' (Dept of Health: Seeking Consent p.3)

Therefore it is also reasonable to speculate that only recent consent might be ethically, and perhaps even legally, valid. This would apply particularly in the instance of people whose mental capacity is dynamic, i.e. subject to rapid change.

I strongly recommended, therefore, that further advocacy provision should be offered immediately prior to the time when changes were going to be made, and that information given by each resident during the first consultation should be re-verified as current.

Consent and Inclusion/Exclusion

'It may be morally wrong to pass over someone who is vulnerable and unable to agree to the appointment of an advocate but whose quality of life might be vastly improved by the attention of such a person' (Dean p.67)

This issue was not as pressing in the current context as it might be in other circumstances, because of the assurance that alternative provision would be made for those residents who chose not to or were unable to accept the offer of advocacy. However, and despite allowing for the implications of the *'assumption in favour of capacity'* outlined in recent legislation, I personally feel that it is wholly reasonable to assume that residents who are unable to voice their preferences, but who are willing to engage with an advocate in a manner that could reasonably imply consent, would prefer circumstances within their environment that meet and fulfil their needs. Therefore, in the absence of instruction or explicit permission, I feel that it is reasonable, fair, and inclusive to offer provision based on professional observation of the resident's situation, and if available, details of their personal history (ideally recent). Because of this I was grateful that on occasion staff gave me access to resident's case notes, including their current care-plan. I only asked to see these when I felt that they might offer valuable information that would be likely to contribute to the resident's future wellbeing, and that I could access in no other way.

Confidentiality/Sharing Information

'For a person's consent to be valid, the person must be:
- Capable of taking that particular decision ("competent")
- Acting voluntarily (not under pressure from anyone)
- Provided with enough information to enable them to make that decision (Dept. of Health: Seeking Consent p.3)

I decided not to share information about the proposed changes at with clients whom I felt were unlikely to be able to cope intellectually, emotionally, or psychologically with such a prospect, particularly because of the length of time before they would take place. Instead I asked both open and specific questions about aspects of their present and former circumstances in order to try to determine what their current preferences with regard to accommodation might be.

I realise that this approach might be interpreted as depriving the client of the right to know, and that my judgement in the matter might reasonably be deemed subjective, however I feel that it represents an inclusive and compassionate way of eliciting information, and avoids creating unnecessary anxiety that would in itself be detrimental to the resident's wellbeing.

As already mentioned, when residents showed willingness to engage, but were unable to give clear permission or to answer questions coherently, I obtained information about their circumstances from sources other than direct interviews. This included verifying with relatives and/or staff anecdotal information given by residents whose conversation suggested elements of confabulation.

On several occasions family members, who sometimes had strong opinions regarding the character and needs of the residents to whom they were related, offered unsolicited information. When this happened I remained mindful that it was my duty to represent the best interests of the *residents*, and to respect their confidentiality.

The final general conclusion that I have reached on the subject of confidentiality when working with residents with dementia is that an advocate should only deviate from the practice offered to residents with capacity when it is demonstrably in the resident's interests to do so.

Touch

- *Non-verbal communication abilities of the demented are comparable to those of the non-demented*

- *Positive affective non-verbal messages elicit positive verbal and non-verbal responses in the demented*
- *Social conventions are apparent even in severely demented people (Perrin and May p.89)*

Despite the current climate of litigation, I have found that the appropriate use of touch, i.e. touching someone's arm to reassure, can help to create trust and enhance communication with people with dementia. I also feel that it can be a legitimate tool in trying to establish contact with people who initially present as too withdrawn to engage verbally. In using touch with residents at I have asked myself the following questions:

- How might touch enhance/facilitate communication?
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- Is there an established ethos of touch within the client's current environment? (I observed that members of staff often used touch to reassure with obviously beneficial effect)

- Does the client initiate touch?

- Can clues be observed in the client's response to touch (i.e. do they shrink from it or does their posture open or soften)?

- What is my (the advocate's) felt sense regarding the client's response to touch?

My experiences in this context, and in previous settings, suggest that when used sensitively touch can indicate acceptance, ease in another's company, or reciprocation. I believe that it can contribute to the inclusion of people who might otherwise be deemed unable to engage with an advocate.

Conclusion

This paper has considered the ethical issues raised in part one of the article in more detail and should ideally be read in conjunction with the range of responses to the issues of social isolation, autonomy and privacy previously highlighted for older people with dementia. To reiterate, it is simply a personal account of the reflective thinking that I undertook as I learned from the residents during the advocacy process, and I offer it with the desire to make a small contribution to what I hope will be a growing field of knowledge and expertise.

Acknowledgements

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