

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

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Part One

Introduction

This article consists of two papers that will describe the experience of conducting person-centred advocacy with older people who have dementia. The first part tells the story of delivering an advocacy project based in a residential home and considers the issues and themes that emerged from that process.

Part two explores and discusses the ethical considerations arising from and inherent in this situation.

Overall, it is a personal account and aims both to give voice to the people with dementia and insight into the practical aspects of the project, as well as the reflective processes of the main author. For this reason it is written in the first person.

Background

I was appointed Older Person's Advocate by an independent agency offering non-instructed advocacy within a London borough in June 2004 on a six-month, part-time contract. The purpose of my post was to offer advocacy to residents of a local authority funded residential home housing approximately 45 residents, which by the year 2006 would no longer meet statutory requirements for residential accommodation for older people.

This was my first experience of formal advocacy, however I was already working as a counsellor with older people, some of whom had complex needs, including dementia. As the concept of offering advocacy to people with dementia is relatively new, and as I was given to understand that a substantial number of the residents I would meet had been diagnosed with dementia, or were exhibiting behaviours that suggested some level of cognitive impairment, I was therefore particularly interested in the clinical and ethical aspects of the work, and my intention is to describe my subjective impressions of these areas, as well as the reasoning which formed the advocacy process.

The Framework

Although aspects of the consultation process changed as it evolved, the initial framework was set out as follows:

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- There should be clear evidence of inclusion, i.e. how residents were offered access to the service.
- Following from this, an assessment form was developed, similar in nature to an occupational therapy assessment, covering medical condition, social situation, functional abilities, and cultural and personal issues. This was intended to act as a prompt for me as an advocate to ensure that residents were given every opportunity to speak about the wide variety of issues that might affect their choices relating to accommodation. It was also intended to show that, as far as possible, the same areas had been covered with each resident, and that they had therefore been offered equal opportunity. In addition the information gathered could be of use if, as had been suggested, an advocate was involved at the time when changes to the resident's accommodation were actually implemented. It also would have the value of preserving information where a resident's ability to communicate had declined in the intervening period.
- At the end of the process the assessment form would be condensed into a feedback statement, to be agreed with each client individually, which could then be presented to the manager on his or her behalf. Subsequently, because a high proportion of the residents chose to accept advocacy, I decided to try to agree the essence of the feedback statement at the time of the final interview, where possible clarifying with each resident the points they wished to convey.
- In addition, in the possible event of similar themes emerging, I decided to ask permission from residents to present aspects of their feedback collectively should this seem appropriate, in the hope that their combined voices might have greater impact. An example of this might be the preservation of friendship groups that had developed within the home. Collective presentation might also offer confidentiality for residents who felt too vulnerable to raise an issue as an individual, or who felt that an issue that they would prefer to raise anonymously might be easily traced back to them.
- As far as possible information would be recorded in a way that was constructive rather than emotive, providing this did not deny residents the opportunity to express strong opinions or feelings. This decision arose because it reflected the resident's general preference, because it offered the most likelihood of a positive outcome, and also because during early interviews some residents admitted that they felt too vulnerable to express what might be perceived as open or unduly harsh criticism. Subsequent interviews also confirmed this impression.

Timing and Prioritising

Because it was not possible to anticipate how many residents would accept advocacy, or how much time each interview or series of interviews might take, or how many subsidiary interviews with families, carers, or healthcare professionals there might be, it was decided, as far as possible, to keep time frame agreements open. I hoped by so doing

to enable the process of advocacy to remain flexible and responsive to the resident's needs.

It was initially agreed to prioritise those residents who might be expected to be most vulnerable, i.e. those with dementia or without next of kin. In practice the consultation process evolved more organically, with some interviews arising via spontaneous introductions from residents I had already spoken to, and others at the behest of relatives. In addition, although I was given to understand that 11 residents diagnosed with dementia lived in a specific unit within the home, I subsequently interviewed several people living in other parts of the home whose evident confusion and memory loss suggested some form of cognitive impairment.

Furthermore, residents whose cognitive or communicative abilities had been impaired by strokes, mental health problems, or hearing or sight loss also appeared to be highly vulnerable. I quickly reached the conclusion that, without detailed medical and personal histories it was difficult to prioritise effectively in advance, and my practical solution was to approach each resident without assumption, and to be prepared to allocate to them whatever time their specific needs required.

Initiating Resident Contact

It was agreed that advocacy would only be offered to permanent residents, i.e. not to those in respite. Having obtained a list of residents, I spoke to each unit manager to ascertain:

- The best time to conduct interviews with individual residents. Some for instance attended day centres, others might be more amenable to approach at certain times of the day for personal reasons, or because of the effects of medication
- Which residents might be likely to experience communication difficulties. For example provision could be made for an interpreter for clients whose first language was not English
- Whether any residents might present a risk during interview, or might be likely to feel threatened or become agitated

In addition I drafted separate letters to residents and to members of staff introducing myself and explaining my role and why the consultation had come about. Where appropriate I presented the resident's letters at the time of the initial interview, refraining from doing so only if I felt that the contents might be misinterpreted in such a way as to cause unnecessary alarm. It was agreed that individual residents should be given at least three opportunities to choose to accept advocacy, although in practice this was rarely necessary.

Where possible I sought initially to establish an informal rapport with residents, to try to create familiarity and trust. An example would be sitting in on a quiz in the dementia

unit, or when working individually chatting about a resident's personal history or interests, which often in itself yielded useful information. On several occasions residents sang to me – so I joined in!

Confidentiality

For residents with capacity I set out boundaries similar to those associated with a standard advocacy or counselling setting. This meant that they would be offered total confidentiality, that nothing would be disclosed without their permission, and that the essence of their feedback statements would be agreed as clearly as possible before being submitted to the manager overseeing the possible changes to the home, who would also treat all individual statements as confidential. The one exception to this arrangement was that I agreed to communicate any adult protection issues to the manager at the time they came to my attention. Fortunately this proved unnecessary.

In addition I decided to be led by residents regarding their need for privacy at the time of interview. Therefore they could choose to be interviewed in their room, in the presence of a relative or friend, in a communal setting, or in one case in the garden area.

I have found the issue of confidentiality in relation to working with residents with dementia to be an extremely complex one and will return to it in part two.

With the exception of members of staff at the home, I only sought information from healthcare professionals at the specific request of individual residents. I also normally only approached family members for additional information with resident's permission. However I felt that in the case of severely confused residents, or in the case of a resident who spoke no English, input from relatives might have offered a fairer opportunity to identify or clarify their needs. This is an example of the dilemmas facing a person-centred advocate in trying to maintain the principle of autonomy when working with cognitively impaired people.

Where relatives approached me independently, I sought to establish that the information they gave me accorded with the preferences of the resident, and at all times tried to establish and record what the resident wished to say. I also recorded all sources of information that had not come directly from the resident.

Communicating with Residents

I employed simple counselling skills such as reflection and paraphrasing to clarify meaning and elicit information, also to try to ensure that the residents felt that they were being heard and their issues were being represented accurately. Where meaning was not immediately clear, I also found it helpful to validate the emotional content of what was being said, particularly if this meant acknowledging strength of feeling that might have accumulated through frustration at not being able to express meaning clearly or through the feeling of not being heard previously.

While interviewing residents, I was mindful of the psychotherapeutic concept of 'presence'. In other words I tried to be aware of ways in which my own demeanour might put the resident at ease and facilitate communication. I also took cues from the resident regarding the formality or informality of the interview, proceeding in whatever way they seemed most comfortable with.

I found that some residents participated actively, expressing clear preferences, initiating subsequent contact, and sometimes introducing me to their friends. Others might be described as acquiescent: 'You have to do your job'. I tried to balance these reactions, which might not have been typical of an individual resident's normal behaviour and attitude, by observing and recording any information that might help to represent their current needs, sometimes obtaining additional general information from members of staff. Wherever possible I checked these observations with the resident, regarding the need to reflect their views as paramount.

Resident feedback

Of the 36 permanent residents, 30 accepted advocacy. In general, residents were positive in describing their experience of living at the home. Many had clearly developed a personal rapport with members of staff and in my opinion the staff demonstrated a consistently high standard of care towards the residents which was reflected in their feedback.

Emerging Themes

As the consultation proceeded I became increasingly aware of a range of responses to the issues of isolation, autonomy and privacy. I also recognised a relationship between these themes and questions concerning the relative merits of residential and sheltered accommodation, the latter being considered as a possible option for some of the residents.

Social Isolation, Autonomy, and the Desire for Privacy – Residential or Sheltered Accommodation?

Any change of accommodation represents a significant transition for an older person, particularly one with dementia, and I suggest that the following questions might play a useful part in deciding appropriate accommodation:

- Will social isolation potentially be increased or decreased by a change of accommodation?
- What factors might influence this?
- What support systems are necessary to avoid the risk of isolation?
- How do these relate to the client's personal and clinical history?
- If faced with a move from residential to sheltered accommodation, how capable is a resident of reversing any loss of autonomy stemming from institutionalisation?

- What skills might he/she need to regain to return to a more independent setting?

Furthermore I feel that it should not be assumed that living in a residential environment precludes residents from experiencing a sense of isolation. During the consultation period residents described a sense of loneliness because:

- They believed their cognitive abilities to be markedly superior to those of the majority of other residents, and therefore felt deprived of satisfying conversation
- They felt that their specific cultural needs were not being recognised.
- They felt distanced from the world beyond the home, and therefore unable to maintain contact with valued acquaintances and 'life outside'
- They did not feel that the home was an appropriate environment in which to entertain friends

One 'mixed' unit housed residents whose needs and capacities varied markedly, including people with dementia, people with mental health problems, and people with unimpaired mental and emotional faculties. Here I noticed evidence of what might be described as 'negative empathy'. In other words higher functioning residents often made a conscious effort to dissociate themselves from the others in order to maintain their sense of personal identity. I feel that this reaction is likely to have stemmed from a fear saying: 'This is what might happen to me'. This issue clearly also posed challenges to members of staff, who were called upon to respond to a wide range of apparently contradictory needs. Although no resident with dementia commented on this phenomenon, I would be surprised if they were entirely unaffected by it.

Individual resident's ability to maintain a sense of privacy often seemed to relate to the extent that they managed to personalise and therefore 'own' their room. Therefore those whose rooms contained family pictures, plants, books and other artefacts showed less anxiety about the possibility of intrusion. One resident with significant short term memory loss astonished me by producing a dozen of her own oil paintings from behind her bed, thereby changing an apparently sparse room into an art gallery. In addition residents whose mental and physical condition allowed them to spend time away from the home, or to go out into the garden, were able use these resources as means to gain privacy. I feel that it is important to consider factors such as these when considering both the location and layout of accommodation for elderly people.

Identity and repeated stories

'Talk to patients with Korsakoff's syndrome or Alzheimer's disease, and you will sense the terror behind not knowing who you are, what happened yesterday, and what will happen tomorrow. Part of my sense of self depends on my being able to go backward and forward in time and weave a story about who I am, how I got that way, and where I

am going, a story that is continuously nourishing and self-sustaining. Take that away from me and I am significantly less' (Spence cited McLeod p.92)

I feel it would be of immense value in the field of dementia to initiate or continue research that explores the connection between the emergence of significant narratives (i.e. those stories or aphorisms which are frequently repeated) with the possible desire or instinct to preserve or recreate a sense of identity.

'In the people I have known who have succumbed to the [Alzheimer's] disease, there still remains, at the end, a primary and incorrigible core of selfhood' (Perrin and May p.41)

For me, the simple question that talking to people with dementia provokes is: what is so important to this person that it merits such continual and often heartfelt repetition? Often the sense I have been left with is that, when listening to a description of some apparently mundane event or activity, for instance a memory of a former home or neighbourhood or a glimpse of a lost relationship, I was being told: 'This is who I am'. Again and again I have been reminded how much of our identity can derive from the simple habits of our life.

Conclusion

This paper has introduced the process involved in carrying out person-centred advocacy for older people with dementia. The main themes have been described from a personal point of view. In part two the ethical issues will be considered in more detail.

References

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