Communication and consultation

Exploring ways for staff to involve people with dementia in developing services

Kate Allan
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“Finding a voice means that you can get your own feeling into your words and that your words have the feel of you about them.”

Heaney (1980)

“Dementia sufferers sometimes seem to have a heightened awareness of body language, and often their main meanings may be conveyed non-verbally. In the case of those who are very severely impaired in cognition, it seem probable that the words and the sentences are at times more of an accompaniment or adornment than the vehicle for carrying the significant message.”

Kitwood (1993)
I am very grateful to all the people with dementia and the relatives who supported and contributed to this work.

My admiration and thanks also go to all the staff and managers who took part, and their colleagues supported the work. The services who participated directly were:

Ardnablane Royal Scottish Masonic Home
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My supervisor, Mary Marshall, was extremely supportive at all times and my colleagues at the University of Stirling provided much needed back-up. Particular thanks go to John Killick for orientation, inspiration and always understanding when other projects had to wait.
This project forms part of a stream of work looking at the subject of communication with people with dementia, specifically exploring ways in which staff can consult them about their views of services. It is part of the wider trend towards recognising the continuing personhood of people with dementia, and developing person-centred models of care.

It follows on from a previous study undertaken by Malcolm Goldsmith at the Dementia Services Development Centre (DSDC) in Stirling, also funded by the Joseph Rowntree Foundation. This project resulted in the book *Hearing the voice of people with dementia: Opportunities and obstacles*, published by Jessica Kingsley in 1996.

The current project set out to explore how staff in a variety of services can encourage their service users with dementia to express their views of the help and support they receive. The emphasis was on the process of how staff can help people to express their views, rather than on what people said about services. Our interest was on looking at what could be done by frontline staff without extensive training within the scope of ordinary services.

It was a small-scale, exploratory piece of work, and this report takes a descriptive, impressionistic form.

Forty members of staff in a set of 10 day, residential and nursing services took part. Domiciliary services were not included in this phase of the research. Thirty-one people with dementia participated in the project. Many of these people were in the later stages of their condition and had significant difficulties with communication.

The aim was to develop and carry out individualised approaches to communication and consultation, which were devised by the staff in collaboration with myself. The fieldwork therefore comprises a set of small-scale initiatives, some of which continued over 10 months. Others took place over only six weeks. My role was to support staff in exploring the approaches, rather than doing direct work with people with dementia.

A collaborative style of working was used in which there was explicit recognition of the existing knowledge and skills of staff in the area of communication with people with dementia.
During the course of the project staff were encouraged to reflect on their own practice and experiences of using the various approaches. An individualised, developmental approach therefore predominated.

The issue of consent was explored in the project, and this work has implications for both future research and practice.

A wide variety of different approaches were tried in the project as a whole, and from this we have a considerable body of evidence that many people with dementia, including those with significant communication difficulties, can, with the right kind of support, take an active role in communicating their thoughts and feelings about services.

The emphasis on the process and the experience of staff in carrying out work of this type has enabled us to learn a great deal which has direct relevance in the effort to help services for people with dementia generally to incorporate service user consultation into their pattern of care.

The main outcome of the project will be a set of training materials supporting staff and managers in exploring the area of service user consultation.
Introduction

This project explored how staff can help people with dementia to express their views of services. We were interested both in what we could learn about various approaches of staff to consultation work with this group, and also what it would be like for staff trying to carry out this kind of work in ordinary service settings.

As projects go, it is not like most others, which make plans and carry them out in a fairly intentional fashion. We had no pre-planned methodology. The aim was to try out a whole range of different things – only some of which had been thought of at all at the start of the enterprise – with different people in different situations, and to try to make sense of what was happening as we went along. It had an openness, an unfolding quality which meant that at any one time I, as the researcher, was not sure what was going to happen next or how I would respond to it. In this way, as well as others, the nature of the project mirrored that of the services in which the actual work was taking place and also the experience of staff who must adapt to a degree of unpredictability, and develop strategies for responding to what is going on at a minute-to-minute level, as well as keeping longer-term goals in mind.

At a further and most crucial level, it is perhaps not too fanciful to imagine that the way that the project evolved mirrored the experience of the person with dementia. Whether through the nature of the condition or because of the way we respond to it or both, the individual is forced to tolerate the experience of disconnectedness and unpredictability, and marshal whatever resources they have to find a way through the messiness of situations, people and their complexities, and the filter which is our own personal way of making sense of ourselves and the world out there.

This report is an attempt to convey the spirit and some of the details of what was achieved, and to consider some of the implications which emerged. In line with its exploratory and impressionistic nature, it is told from my point of view, but the words of the people with dementia and the staff who took part are quoted as extensively as possible. On account of the characteristics of the project, all the factors and influences which are normally considered ‘noise’ and filtered out in standard research enterprises and reports were of central relevance here. While this may make the messages more difficult to discern or the whole seem messy, this is the reality of the situation and reflects the stage we are all at in terms of tackling these issues. If we want to carry out the kind of research which has the potential to change practice, we cannot afford to ignore what things are actually like in the day-to-day world of services.
Things have been changing fast within the dementia world. Only five years ago the idea of asking people with this condition what they think about the services they use would have seemed at best misguided, at worst reflective of a basic misunderstanding of the reality of dementia. Images of disintegration, emptiness and loss predominated in thinking about dementia, as evidenced by book titles such as *The vanishing mind* (Heston and White, 1991) and *Alzheimer’s disease: Coping with a living death* (Woods, 1989) and descriptions of the individual with the condition as ‘an uncollected corpse’ (Miller, 1990).

Although public characterisations of dementia unfortunately persist in being highly nihilistic, and we all need to continue to challenge our negative assumptions, those who work directly with people with dementia are now operating in a very different culture. Through the published work of Tom Kitwood (1997), John Killick (1997a, 1997b) and others, and the direct experience of many others, we are now at the stage of recognising and learning to engage with the unique, active and ongoing person, who continues to struggle to make sense of their world from within the condition.

Although local provision often remains patchy and difficult to access, a much greater range of services is now being explored and developed, and expectations of continued health and wellbeing, despite the progressive nature of the condition, are very much greater.

The centrality of communication to good care now enjoys widespread recognition, although we have much to learn about exactly how we can enhance our understanding and range of skills. Within this, service planners and providers have largely now become aware of their responsibilities to consult users, and are keen to learn about ways of doing so.

**Legislative and policy context**

Legislation and policy on the subject of service user consultation is quite clear. Service planners and providers must find ways of consulting users about their views, and involving them in influencing the design and delivery of the service.
Communication and consultation

The first document which signalled progress regarding the involvement of service users of all types was the 1990 NHS and Community Care Act. This stipulated that “Each local authority ... shall consult ... voluntary organisations ... or ... private carers”. Note that this did not state that service users themselves had to be consulted. At that time it was assumed that organisations or family carers could act as a legitimate proxies. In the case of people with dementia, as with other groups, it would still have been considered impossible meaningfully to ask people directly affected about their needs and preferences.

The second major document which advanced the position in this respect was the *Health of the nation* report published in 1992 (DoH, 1992). This went considerably further than the 1990 Act, and stated that service providers and purchasers:

... have a duty to consult fully with users and their carers in the drawing up of community care plans [and] will need to ensure that service users are enabled to define their own health and social care to their maximum ability.

The appearance of the word ‘user’ meant that there was no mistaking that the people affected by conditions of various sorts were to be included in the process of consultation.

More recently (Filkin, 1999), the current government’s move away from the old culture of competition and the internal market emphasises continuous improvement, value for money, accountability and openness to local people, and regular monitoring and review. Again the principle of involving and consulting users in planning and implementing services is to the fore.

Previous research

Some small-scale studies looking at the feasibility of involving people with dementia in service user consultation work have been undertaken (for example, Phair, 1990; Lam and Beech, 1994; Sperlinger and McAuslane, 1994; Sutton and Fincham, 1994; Proctor, 1998; Dabbs, 1999). All these studies adopted an interview format with researchers external to the services, asking people about their experiences and opinions. Participants in the research were all people who were considered to be in the earlier stages of their condition, and the emphasis was on purely verbal communication. A different approach to consultation was explored by Bamford and Bruce (2000). They organised and ran group sessions where people with dementia were encouraged to describe what types of outcome they sought from community care services. All of these studies concluded that people with dementia have opinions about the services they use and do wish to communicate these views.
Origins: where we have come from

Barnett’s (2000) research used a more in-depth methodology in evaluating a new care facility from the point of the view of the residents. She conducted a series of interviews which were analysed for themes, with a particular interest in metaphorical expression. Again, the results indicate that such people have opinions which are of direct relevance to service planners and providers.

Work by Mozley et al (1999) demonstrated that people living in nursing homes whose cognitive impairment (as measured by the Mini Mental State Examination) was considered severe were nevertheless able to take part in discussions about their experiences.

Service user consultation work is beginning to be included in work which has a broader remit. In their exploration of the use people with dementia make of community care, Moriarty and Webb (2000) sought the views of people with dementia about their experiences of services. Keady and Gilliard (2001: forthcoming) asked people who were undergoing assessment for a possible diagnosis of dementia how they felt about the procedures.

Cheston et al (2000) have undertaken a review of some of the work on involving users, organising the material under different approaches to consultation (for example, semi-structured interviews, observation, advocacy). They also examine ethical issues such as consent, confidentiality and empowerment.

While all this work has been of value in demonstrating the feasibility and usefulness of service user consultation work with people with dementia, it all shares certain important limitations. If the involvement of service users is going to become a routine part of service delivery, it is clear that it has to be those actually providing care who undertake the work, rather than personnel external to the organisation. It also has to form part of the ongoing routine of care, rather than be carried out as a ‘special’ exercise. While it is now clear that it is possible to undertake interview-type approaches which yield valuable information with many people with dementia, as most people move through the condition communication becomes progressively more difficult. We therefore need to develop a range of ways of consulting people concerning their needs which can be used and adapted over time.

Between 1993 and 1995, Malcolm Goldsmith took a broad look at the place of communication in the care of people with dementia. He completed a review of literature on the subject, and undertook a large-scale consultation exercise with workers in the field, posing various questions around theory and practice in the
area of communication. He also carried out interviews with people with dementia and their relatives. This work (which was also funded by Joseph Rowntree Foundation) resulted in the book *Hearing the voice of people with dementia: A carer’s handbook*. (A manual for relatives [Innes, 1997] and one for staff/volunteers [Goldsmith et al, 1997] were also produced. A quiz game was also devised [Kindred and Goldsmith, 1997].) The main conclusions were that:

- communication is possible
- challenging behaviour can be a form of communication
- dementia affects different individuals in different ways
- the environment has an important effect on communication
- we need to give attention to issues of pacing and timing in communication with people with dementia
- there is a need for early diagnosis
- communication is a skilful task.

It is fair to say that this work put the subject of communication in dementia care properly on the map, and since its publication there has been a dramatic increase in the amount of research and service development initiatives looking at this topic.

Goldsmith’s work on communication gave a positive message, and made the challenge which faced service providers clear: that communication is possible, but it is our responsibility to find ways of overcoming the obstacles which dementia places in the way of the individual.

Linked with the set of conclusions regarding the place of communication in dementia care generally, Goldsmith identified a range of possible ways in which staff in services could go about finding ways of hearing the voices of those in their care. They were as follows:

- speaking to people on a one-to-one basis
- bringing people together in small groups
• facilitating the use of preserved skills such as typing
• studying non-verbal communication, for example challenging behaviour.

These ideas were couched in very general terms, and clearly needed to be tested out in practice. This was the main task of the present phase of the research – to explore the use of these approaches in everyday service situations.

**The current project**

Whereas previous research had aimed to find out what users thought about services, the emphasis in the current work was on exploring the *process* of undertaking service user consultation, in other words how we can find ways of helping people to express their views. Another distinguishing feature was that the intention was for it to be the staff in the various services who undertook the direct work with service users, rather than myself.

In order to do this I set out to make links with ordinary service settings in which a variety of different approaches to service user consultation could be tried. The next chapter describes how this was done.

**Summary**

We no longer think of the person with dementia as an ‘uncollected corpse’ (Miller, 1990). It is now widely recognised that despite the changes brought about by dementia there remains a person who has thoughts, can feel emotions and has preferences and individual needs.

Although these realities are now generally accepted and legislation makes clear requirements of service providers, we are still at an early stage in terms of finding ways of involving people with dementia as fully as possible in designing and delivering services.

We already have a small but convincing body of evidence that people with dementia want to be involved in decisions about their daily lives. The current challenges lie in exploring specific ways of doing this with individual service users. The general need is to place the person with dementia at the centre. Issues such as pacing, timing, approaches and content of consultation about involvement need to be given careful thought. Open-mindedness is vital. People may not always want to be involved in the way that professionals think they do.
The first few months of the project were devoted to establishing links with a set of services where the fieldwork could be undertaken. (This process actually continued throughout the project, with links being established with some services within the final six months of the whole period.) Contacts were made in a variety of ways, but mainly through individual services expressing an interest in being involved, or an approach being made to settings through recommendations and other contacts.

For each service there was a series of initial discussions with managers, who in turn consulted with senior managers. If the decision to go ahead was made, this led to more specific planning and, for many of the sites, formal submissions to, for example, Ethics Committees or Research Access Procedures.

Following this I then met the staff who would potentially be directly involved. For most of the sites this was done through the organisation of an introductory workshop conducted by me. (This event and its follow-up is described in detail in Chapter 3.) In some cases a process of negotiation then took place within the services to decide who from among the staff group would take part.

Once links had been made with particular members of staff and formal permission to proceed had been granted, the next step was to identify potential participants from among each group of service users. Various considerations were brought to bear on this process, including who from among the group of service users the practitioner knew well and might be willing to help with the project, how their relatives might feel about this prospect and, since we were keen to include people who experienced a wide range of communication challenges, the individual’s particular strengths and needs in this respect were also taken into account.
A specially devised Consent Procedure was used in the project, and this and the issues raised in the course of this stage of the work are discussed at more length in Chapter 6.

Once the person had reached the appropriate stage of the Consent Procedure it was possible to start thinking about trying out different approaches to communication and consultation. Again this process is described fully in Chapter 3.

The actual fieldwork phase followed on from this. In the sites which started first this lasted approximately nine months. The shortest phase of fieldwork lasted only ten weeks. More detail about the nature of the fieldwork is provided in Chapter 4.

After the completion of the fieldwork phase, there was a staff feedback exercise where all participating staff were given the opportunity to comment on various aspects of the project, and their involvement and perceptions. Copies of the questionnaires used are included in the Appendix, and material from this exercise is incorporated in several chapters of this report.

Personal letters thanking participants and staff were sent out, and work was begun on a report for each site. Consultation with staff over the content of the report was undertaken, and comments and suggestions were integrated. All these stages are depicted in Figure 1.
**Figure 1: Stages of collaboration**

1. Identification of service
2. Discussion with managers
3. Agreement to participate
   - Process of obtaining ethical approval
   - Introductory workshop with frontline staff
   - Identification of potential participants
   - Implementation of consent procedure
   - Developing ideas for approaches to communication and consultation
4. Fieldwork
5. Feedback exercise
6. Production of site-specific reports
Participating services
Through these processes, 11 sites took part in the project. These included:

- Residential homes: 4
- Day centres: 3
- Day hospital: 1
- Nursing home: 1
- Long-term care ward: 1
- Counselling service: 1

In all but two of the services, work was undertaken in a prospective way with initial discussions and planning leading to fieldwork which took the form of staff trying out various approaches to communication and consultation. In the case of the counselling service, work took the form of a retrospective analysis of tape-recorded discussions, and in one of the day centres a retrospective analysis of casework undertaken with one person by a student social worker was carried out. Detailed discussions of these retrospective initiatives are not included in this report.

It will be noted that no domiciliary services are included in the sample. There were also no services specifically for people from ethnic minorities. These are recognised as important omissions. It was intended that such services would be involved, but due to limitations in resources this did not prove feasible. There are plans to include home-based services in a subsequent phase of the research.

Although the service settings were ordinary in the sense that those who used the service, staffing levels, and so on, were typical, it is only fair to make clear that in each case collaboration was pursued because of the services’ demonstrated commitment to innovative practice and motivation to contribute to the work. This meant that the settings which contributed to the project cannot be considered a representative sample.

Depending on exactly how direct participation is defined (and restricting numbers to those who work is discussed here) a total of 40 members of staff in the various services took part. The breakdown in terms of professional status is as follows:

- Social care officers (residential): 20
- Psychiatric nurses: 5
- Nursing home care assistants: 4
- Social care officers (day services): 2
- Nursing assistants: 3
Communication and consultation

- General nurses: 3
- Home manager: 1
- Day centre manager: 1
- Occupational therapist: 1

As is evident from the above, the majority of staff who took part were unqualified.

**Participating individuals**
In total 31 individuals with dementia took part, seven men and 24 women. However, this report discusses work with only 25 of these participants. The breakdown according to which service they were using is as follows:

- Residential homes: 11
- Day centres: 5
- Day hospitals: 3
- Nursing home: 3
- Long-term (hospital) care: 3

With regard to identifying participants as having dementia as opposed to some other condition, I relied on the knowledge of staff, known history, and previous medical input. There was no formal attempt to classify participants in terms of the severity of their dementia, and no formal assessment of their difficulties with communication was undertaken. It was felt that this was not consistent with both the exploratory nature of the research, nor the empowering values of the project.

In line with the aim of exploring service user consultation work with a heterogeneous group, many of this set of people were in the later stages of the condition. Among them a wide range of communication difficulties was represented. Some used very little language, and there were some whose behaviour was considered challenging.

**Methodology**
In methodological terms this project was extremely loose. At the outset there was a clear intention to set up situations where we could try out various approaches to consultation, but only a very general idea of how these objectives would be achieved. The challenge was to find ways of setting up initiatives which:

- were integrated with the particular service settings and their ways of working
New directions: overview of the current project

- were tailored to the communication needs, styles and preferences of the individuals with dementia
- built on existing relationships between the person with dementia and members of staff.

Since the aim was to look at what was possible in ordinary service settings, there was no attempt to create special conditions, in terms of arrangements for extra staff or anything else which would demand an unusual level of organisation, for the work. Also, given the exploratory nature of the project, there was no attempt at the kind of control of variables which would be necessary in more systematic research which aims to attribute causality and to be fully replicable.

The result of these efforts has been the undertaking of many different types of approach by many members of staff within the different service settings, with many different people with dementia, who were themselves a highly heterogeneous group. Initiatives were undertaken on both one-to-one and group bases, although most took an individual form. Almost everything that was done was different from everything else. Examples of approaches used are given in Chapter 4.

This very diverse set of initiatives resulted in the amassing of a large amount of complex and highly differentiated data. This data takes a variety of forms, for example:

- audio recordings of conversations between people with dementia and members of staff
- audio recordings of conversations between me and members of staff
- forms completed by staff
- freeform notes written by staff
- notes written by me about particular pieces of work
- notes written by me during conversations with members of staff
- feedback from the staff about the experience of taking part.
In accordance with the fact that the focus of the study was on the process of consultation rather than its outcome, data was not analysed in an attempt to amass a collection of views on services. Respecting the fact that each interaction, and the evidence of these that could be retained, was embedded in a unique temporal, physical and interpersonal context, no attempts were made to convert data into a standardised format. Again, in acknowledgement of the uniqueness of interactions, no attempts were made formally to compare the outcome of one initiative with any other.

**Outcomes**

It is expected that in addition to the usual forms of dissemination (conference presentations, journal articles, this report and so on), the main outcome of the project will be a set of training materials designed for the use of managers and practitioners and to help them develop their own approaches to service user consultation work.

**Summary**

This project is not about superhuman services. It is about exploring what is possible in terms of communication and involvement in the context of ordinary service settings, which face all the constraints that ordinary services face. The service world did not stop for the practitioners in the different sites!

Attempts were made to include people with as wide a range of communication strengths and needs as possible as would be found in a typical service situation.

The methodology of the project was loose, diverse and aimed explicitly to reflect and accommodate the variety we find in people with dementia, their situations and their relationships to services.

The data which was generated during the fieldwork phase also reflects the variability in the initiatives undertaken.
Given that the main emphasis of the project was on exploring how staff could go about undertaking service user consultation, and the aim was to produce training materials which would help staff to design their own approaches, the process of developing ways of working alongside the staff to explore the possibilities was of major importance. This was crucial not only to the success of the project itself, but also because increasing awareness of staff and service-related factors in consultation work is necessary for developing our understanding of how it can be integrated into the normal working practices of services.

This chapter describes how this was done in the project. We begin with some general considerations.

**The values of the project**
All the work was underpinned by certain basic values. Those relating to people with dementia followed on from and developed those identified by Tom Kitwood (1997) as person-centred. Given that there has been less written about ways of working with staff within a person-centred model, the values which guided this aspect of the work were less well-established. The fact that the methods were novel and would only properly take shape in the course of the work added to the lack of initial definition. However, the principles which were identified at the start of the enterprise (during the induction workshops) and perpetuated as far as possible throughout were that:

- since this is such a new field, we are all learning and therefore there can be no ‘experts’

- staff brought vital resources to the enterprise in terms of their knowledge and skills, and that the project would involve my learning at least as much from them as providing guidance and ideas myself
Communication and consultation

• working on the project would be an opportunity for raising issues and questions and reflecting on the lessons learned

• insights gained about successful ways of communicating would be shared so that benefits could be as generalised as possible.

General versus specific focuses
Despite the fact that the overall aim of the work was to explore approaches to consultation, it seemed necessary to have a much more open and inclusive frame, certainly initially. In many cases it was only by beginning at a very general level in terms of thinking about people, relationships, care practice and communication that more tailored approaches to consultation could be developed. Reasons for starting at a general level included the following:

• to allow practitioners to get used to thinking about communication in a different way – to bring its subtleties and complexities into more conscious awareness

• to allow time for the person with dementia to adjust to the reality of having more attention paid to communication

• to provide opportunities for ideas about more specific approaches to present themselves.

This was achieved in a variety of ways:

• practitioners thinking, talking and reading about the subject of dementia generally, and communication more specifically

• staff being encouraged to approach ordinary tasks with more awareness of their communication potential

• staff being encouraged to think more about how they themselves communicate

• staff reflecting afterwards on encounters and their characteristics in terms of communication.

The balance between focusing on particular issues related to communication, consultation work and more general considerations was paralleled in the ways in
Preparing and supporting staff: starting points in learning lessons

which I worked with staff. In order for any kind of collaboration to take place it was necessary to establish basic rapport, and for this to develop into viable working relationships. It was therefore important to devote time and energy to discussing more general issues for services, service users generally, considerations for staff generally and issues for particular members of staff, sometimes including personal ones. Input of this type was necessary not only to allow relationships to develop, but also for us to come up with appropriate ideas for initiatives and to make proper sense of the outcomes.

Modelling consultation
At all times I tried to convey the idea that the practitioners held a vast reserve of experience, skills and knowledge, and that the recognition and utilisation of these resources were vital to the success of the work. In addition to this, as far as possible I aimed to carry out work with staff in such a manner as to model ways in which people with dementia could be involved in how their care was organised and carried out. From the first contact with the staff (at the induction workshops) the emphasis was on finding out from them about:

- their experience of working with people with dementia
- their views about communication in general, and their perspectives on what constituted successful instances of communication with service users
- their ideas about the feasibility and the success or otherwise of the Consent Procedure
- their ideas about how approaches to consultation could be designed and carried out with particular individuals
- their experiences of trying initiatives out, and their ideas about how approaches could be developed or modified
- their views about the best ways of keeping in touch with me and generally organising work for the project
- their feelings and ideas about ways of documenting work for the project
- towards the end of the project, their feelings about taking part in it and their reflections on their contribution
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- opinions about the content of the report for their site.

Another aspect of the effort to work collaboratively with staff was the provision at all stages of high-quality and personalised information and feedback – for example, feedback from the induction workshop, write-ups of recorded conversations and progress reports. The role of this will be discussed more fully later. Although I am convinced that this way of working conferred many benefits, indeed crucially underpinned the success of the enterprise, it was demanding and time-consuming. It meant that explanations and discussions had to be repeated many times with different members of staff, and that documents and procedures had to be modified to take account of individual circumstances, preferences and needs.

However, this style of approaching the work seemed to be the only effective way to get started in a field which is so open and ill-defined, and where the variables are numerous, difficult to quantify and largely unpredictable. It also provided an opportunity for reflecting on the parallels between research and service provision work, and generated some ideas about how the often apparently unbridgeable gap between them can be addressed.

Developing relationships with staff
Any kind of collaborative venture must begin with effort to develop the types of relationships which will support joint working. This section describes how this was attempted.

Initial contact
Relationships with staff who took part in the project were begun at the induction workshops and developed from there. This session aimed to introduce both myself and the project to the staff and to the services as a whole, and to extend an invitation for particular members of staff to contribute to the work.

The format was fairly open, beginning with a short talk from me about the background and general aims of the project, followed by brainstorming sessions where the practitioners were invited to talk about:

- the meaning to them of the word ‘dementia’
- their experiences of and feelings about working with people with dementia
- the meaning to them of the word ‘communication’
their experiences of communication with people with dementia.

Staff were then asked to think of a recent encounter with an individual with dementia which had gone particularly well, and to discuss the communication aspects of this with a colleague. Volunteers were then sought to describe the incident, and discussion of aspects of it followed. The emphasis in these discussions was on trying to identify the sorts of skills and knowledge the member of staff had brought to the situation, and how they had used these resources to bring benefits both to the person with dementia, other service users and themselves. Invariably these exchanges appeared to be of absorbing interest to staff, and there was a high level of participation and contribution.

During these discussions my role was to draw out the thoughts and feelings of the members of staff, helping them to reach conclusions or generalisations, and to make sense of their experiences within a wider framework of understanding dementia as a condition and how individual persons are affected by it. I also attempted to highlight the sorts of questions and issues which the project hoped to address. Permission had been sought to make audio-recordings of these sessions, with assurances that material discussed in them would not be used for any other purpose without further consultation.

In planning for the workshops I had aimed to move the discussion on to more practical aspects of the work and the challenges which we would face, but in most cases the staff-led discussions took up almost all the time. Where I attempted to focus attention on, for example, the practicalities of identifying potential participants and considerations pertaining to consent, this seemed not to follow on well from previous discussion and, in the absence of clear plans for how to tackle these stages anyway (this was yet to be addressed properly in my own mind), such effort could not have resulted in clear outcomes.

The following are comments from staff collected during a feedback exercise which was conducted at the end of the fieldwork phase. (The purpose of this exercise was to give staff and managers an opportunity to comment on their experience of taking part in the project, and to highlight any messages they felt were of particular importance. Copies of feedback questionnaires for both staff and managers are included in the Appendix.)

In response to the question, ‘Can you remember how you felt about the prospect of taking part in the project at the start, for example at the workshop we had?’:
“Excited as I felt for a long time that communication in dementia was a neglected area of practice.”

“I was looking forward to taking part as I found it very interesting.”

Alongside the sense of enthusiasm, however, there was also a strong theme of uncertainty and apprehension, which is discussed at more length later in this report. The following comment was typical:

“I thought it was a good idea and quite exciting when we had the first workshop, however I was very nervous and unsure about where to start and about my own capabilities.”

Managers echoed this:

“Some staff initially expressed reluctance. I believe those staff were anxious about the additional demands which would be placed on their time. (This was an issue for all staff.) But I believe they were anxious about their own abilities. Others were enthusiastic and keen to get involved.”

The next contact with staff following on from the workshops was the feedback that they received from this. A personally-addressed letter thanking them for their attendance and participation was accompanied by a set of documents which detailed the aims of the project, provided supporting information, and set out the information generated by the brainstorm sessions and points which arose from the discussions. Specific effort was devoted to presenting this material in an attractive and detailed way so that staff could have evidence that their contributions had been valued and reflected on, and could be integrated into a coherent whole.

This step was the beginning of a sustained effort to provide specific and personalised documentation and feedback for staff. Its role and the responses of staff to receiving feedback will be discussed further below, but for now the main point is that this stage of the work seemed to be important in reinforcing the message that the staff were partners in the work and that their contribution was fundamental to its success.

**Subsequent contact between staff and the researcher**

Following on from the initial stages of relationship-building, and once it had been decided who from among the staff who attended the induction workshops
would take part directly, the particular ways in which I would keep in touch were discussed. The options were: site visits, telephone contact and written contact. For some sites all three operated, for others the frequency of visits was restricted by a combination of distance and the fact that only a small proportion of participating staff could be present at any one time. Telephone contact was the main mode of contact for most of the sites, but site visits were also very important not only because they were the main opportunities for face-to-face contact with staff, but also because they gave me the chance to meet participants and other service users, and simply spend time where things were happening.

Arrangements for keeping in touch with staff were made on an individual basis, and varied according to the hours they worked and what were more favourable times for talking, either face-to-face or on the telephone. This sometimes meant arranging visits out of what would be ‘normal’ working hours, and times for telephone calls had to be distributed throughout the day, evening and night, seven days a week. A complex schedule for keeping in touch with staff participants was maintained, but even so (as will be described in Chapter 5), there were many challenges to be faced with this.

Adapting to the needs of individuals in this respect was vital for at least two reasons. The first was simply that it was necessary for practical reasons to do so. It would have been impossible to carry out this kind of research without such a commitment to flexibility. The second reason is perhaps less tangible, but relates to the possible positive effects of my demonstrating a willingness to recognise and almost ‘be alongside’ staff in the reality of working long and often unsocial hours.

There was a further benefit to be derived from this type of approach. Although there was certainly a sense of strangeness for me in, for example, telephoning a member of staff in a residential setting at midnight on a Saturday, this kind of contact provided a ‘window’ on the life of the service – what was going on at the time, how the staff member was feeling and just a little of the atmosphere of the place and its way of life. I particularly appreciated the following which came from one member of staff during the feedback exercise:

“Just one question – do you ever go to bed?”

**Preparing for getting started**

(Discussion of the process of implementing the Consent Procedure and the issues raised by this are discussed fully in Chapter 6.)
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As we approached the point of starting fieldwork it became clear that the process of developing ideas for approaches to communication and consultation with individual participants was highly significant. Because the aim of the project was to develop ideas on an individual basis according to the needs, style and preferences of the person with dementia, rather than implement pre-planned procedures, the process of finding starting points for the work was very important.

This usually happened through a series of conversations between the member of staff and myself, or with a small group of staff and myself. In line with the values of respecting the knowledge and experience of staff, and working within established relationships, the usual approach was to ask staff to talk generally about their relationship with the person with dementia, how it had developed and changed, and to describe any particular incidents or episodes that they considered significant from the point of view of communication. Invariably this led to animated and reflective conversations, which often went quite deep in terms of thinking about the person, their subjective reality and ways of coping with their condition. Staff raised many questions, and sometimes had new ideas and achieved new insights in the course of these conversations. This was particularly noticeable when a few members of staff, all of whom knew the individual, were present. These occasions highlighted the importance of the practice of storytelling, the significance of which in learning and development is beginning to be recognised (for example, Bowles, 1995).

My contribution to this process was to demonstrate interest and develop ideas and ways of thinking by asking questions, offering interpretations and making links between apparently disparate features of the person’s communication style, behaviour and the ideas and feelings they expressed, and between different incidents occurring over a period of time. I also brought a set of ideas and experiences from other sites, and also actual resources such as pictures and objects (further detail is provided in Chapter 4) which could be used in the course of the work. Another aspect of these conversations, which was possibly of major significance in their success, was the fact that I demonstrated interest in the personal experience of staff providing care, including their positive and negative emotions, and the nature of demands that the work placed on them. This touches on the frequently neglected dimension of the ways in which staff derive meaning from the work that they do, and how approaches to practice development must take account of these. This subject is explored in greater depth in Chapter 8.
Examples of the types of comments staff made about these occasions (‘How did you find the face-to-face meetings?’) include the following:

“Good, as [I/we] often remembered things when we were all together in discussion.”

“When everybody was together it was really interesting.”

“These were good as you all got to say your own side of things that others maybe missed out on.”

“These meetings always reinforced what we were doing, that what we were doing was right, and generated lots of ideas.”

It was clear that staff enjoyed the opportunity to speak in this way. The level of involvement in these occasions seemed to indicate that staff were experiencing something which did not happen routinely in the course of day-to-day and week-to-week working. This could have been due to a variety of factors (and most likely a combination of them):

- having time out from the normal routine of work
- being encouraged to talk about the aspects of work which were most significant to them
- being encouraged to talk about their own personal reactions to people and situations
- (in small group situations) having the opportunity to hear about others’ perceptions and feelings
- having the full attention of someone who was interested in their experience and ideas
- the fact that I was an ‘outsider’ to the organisation, perhaps resulting in people feeling freer to express their own ideas and perceptions.

It seemed that as a result of these sorts of discussions, staff came to appreciate properly that their own perspectives and experiences were crucial to the success of what we were attempting to do.
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In addition to the more immediate aims of establishing and developing relationships with members of staff, and generating ideas for approaches to communication and consultation work, there was the more general intention of helping staff to recognise the complexity and subtlety of the knowledge and skills they routinely brought to bear on situations. It was a recurrent observation that staff underestimated the sophistication of their own contributions, and that in order for them to develop further it was necessary to help them to value their existing (often hard-won) resources.

They appeared to be associated with a variety of outcomes:

- increased awareness of complexity and demands of work, and of corresponding skills and knowledge required – leading to a greater valuing of their own contribution

- increased awareness of the complexity and subtlety of the individual’s experience and way of expressing themselves

- increased fascination with the subject of communication, and the possibilities of developing new ways of relating to individuals

- a greater understanding of themselves and their approach to the work

- a greater sense of meaning in the work generally.

Getting started and maintaining momentum

Out of these conversations, ideas for specific things to try emerged and plans were developed. Although there was excitement generated by discussing possibilities, in many cases actually getting started was challenging. This was the time when we had to confront the practicalities of exactly how things were going to be done, what would be needed, and so on, and so there was a feeling of at last being ‘on the spot’. Some of the staff experienced a degree of anxiety as well, since by going ahead they were about to expose their practice to outside scrutiny. There was also the natural apprehension which accompanies trying out something new, and because initiatives were always rather open-ended, the staff were aware that they were going to need to ‘think on their feet’. The following are examples collected during the feedback exercise of the sorts of comments staff made about this phase of the work:

“Apprehensive. Worried not capable to take part. Not experienced enough.”
Wondered how clients would cope.”

“Very enthusiastic but worried about how I would achieve the goals.”

“I was pleased and eager to take part in any small way, but felt that I may not have anything useful to contribute.”

These feelings were not confined to frontline staff. In response to the same question, one of the managers said:

“How am I going to cope? Will I be able to do it – well? Because I was a manager I would be expected to know and do more.”

With some individuals with dementia it was indeed very difficult finding starting points, and took much longer to get going than for others. This was true of those people who did not use much language, or who were in some form of transition (for example, experiencing a progression in their dementia, problems with physical or mental health) or for whom communication had always been a special challenge. It would be fair to say that for a few individuals we failed to get a real toe-hold throughout the whole period of the fieldwork. Staff who were involved with such individuals needed particular support, especially when colleagues alongside them were progressing well with their participants.

Gradually the practitioners got going with their various initiatives, and the outcomes and their reflections on the experience were then discussed with me. If specific feedback was required (for example, transcribing a recorded conversation) this was provided as quickly as possible. Out of feedback from me and further discussion with the member of staff, ideas for continuing the work were developed. Sometimes this involved repeating or varying slightly an approach already tried. Sometimes the experience of the people with dementia and the member of staff suggested an alternative approach. If an attempt seemed completely unsuccessful a change of emphasis or direction was developed.

Once things were underway, keeping up the momentum was difficult in many instances. As will be described in Chapter 5, there were many events which acted against a smooth progression and development of the work. It was frequently necessary to try to find ways of picking up initiatives which had been found previously to be successful after the gaps which occurred for various reasons, and sometimes it was necessary to continue them in a modified form to take account of changes in the person’s circumstances or strengths and needs as regards
communication. Sometimes it was a different member of staff who was taking over from someone who was off sick or had left their post. These situations were particularly challenging as often approaches were based on features of the relationship between a member of staff and the person with dementia.

The sorts of challenges the practitioners faced in getting started and maintaining momentum within this context are likely to be very similar to those faced by staff attempting to integrate approaches to consultation within normal care practice. And perhaps these challenges would be all the more difficult in the absence of someone in my role whose job it was to help to keep people focused and encouraged.

**Documentation and reflection**

As part of the fieldwork phase staff were encouraged to document their efforts. I provided support for them to do this in a variety of ways. Some kept their own style of notes, some completed forms, which were designed for use with individual participants. For some audio recording of their conversations with participants was the main form of documentation. Some did not manage to keep notes themselves, but documentation was undertaken by me during and after discussions of work done.

It was recognised that different approaches to documentation suit different people, and that the nature of the work meant that it was sometimes difficult to keep notes at all. The following were possible reasons for this:

- simple pressure on time
- general disinclination to write (common to many!)
- difficulty finding paper and a pen at the right time
- being in the wrong place to sit down and write notes
- having to wash hands, take off gloves, apron and so on
- the cognitive challenge of switching from one activity to another
- difficulty of capturing details of interactions and observations in words.
Judging by their responses from the feedback exercise, staff were very conscious of the advantages of making notes. They said things such as:

“Helpful to make sense of the conversation, and to refer to when starting a new one.”

“Keeping notes reinforced the content and importance of the study.”

“Good reminders of the work you have done.”

“It was good to have notes to check the differences in different events.”

However, they were very conscious of the difficulties of maintaining the discipline:

“Essential to keep up-to-date with notes. It’s too easy to forget things if they are not written down.”

“Notes need to be done immediately or some things could be lost.”

Part of the challenge related to the complexities of what was under observation:

“Observing and recording behaviour – often difficult as incidents were fleeting (at times). Even trying to complete recording forms immediately after the behaviour could be hard to do, concentration taken up by observation, awareness that small details could be significant, often hard to pinpoint afterwards.”

When documentation kept by staff was made available to colleagues, it often had a positive effect on the perceptions and sensitivity of other staff to communicative behaviour on the part of the person with dementia. Indeed in some cases breakthroughs in understanding occurred when observations made by staff at different times as part of the project were put together, and suggested changes in routines and practices:

“Increased confidence in recording communication in notes – it is maybe more likely to be seen as relevant since the project.”

“I write more in W’s contact notes and everyone reads them and sometimes ‘copy’ so I hope they are listening to him too.”
However, despite these obstacles and challenges, the staff did a great deal of very valuable writing. It became clear in the course of the fieldwork that the various forms of documentation constituted an extremely important part of the process of learning about communication. Sometimes this took place privately, or in conversation with colleagues or with myself. As described above, conversations about incidents or the use of particular approaches often led to the development of new insights and further ideas. It was much more than simply a way of recording data.

The importance of providing feedback

In common with other aspects of the project, ways of doing this evolved as the work developed and took shape, but the importance of providing feedback to staff was anticipated from the beginning. We know from studies of learning processes that feedback on performance is a vital ingredient, and that its positive effect is heightened if it is immediate and specific.

It was impossible always to come back to staff immediately with feedback, but what was produced was always specific to the particular pieces of work they were undertaking, and as far as possible addressed the aspects they were most interested in or concerned about.

Feedback took various forms:

- informal – during discussions, both face-to-face and on the telephone
- formal – in the write-up of the induction workshop, in reports of particular meetings/telephone calls, in monthly progress reports, write-ups of recorded conversations.

The ideas and information staff made available were also incorporated into the types of forms described above, so these constituted a form of feedback too.

It is likely that feedback in its various forms played several roles. The first was of general encouragement and reinforcement of the importance of what the staff were doing. The following comments from staff illustrate this (in response to the question, ‘What do you think of the written feedback [for example, workshop write-up, blue reports, reports of recorded conversations etc]?’):

“Excellent, positive feedback which was reassuring and rewarding.”

“These were great. I actually thought these made me realise how well I had communicated with J.”
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The value of an individualised approach was highlighted by one of the managers who said:

“I liked the idea of individual reports to each staff member. It made it more personal.”

Another function of the feedback was to draw attention to the detail and complexity of what had been discussed or carried out. Such detail was often simply not remembered (a natural consequence of the limits of human memory), or was not regarded at the time as being special or important. For example:

“The report of the recorded conversation was very interesting and highlighted points which I did not remember had been spoken about.”

“Reading the reports you can’t believe you covered so much.”

Further, seeing things written down gave them a status that they seemed to lack (at least in the eyes of the member of staff) when they were simply private thoughts or even sometimes under discussion. This is illustrated in the following:

“It looks so much better on paper.”

“It was quite surprising how a small amount of work, such as tape recording, could seem so much once written up ... it also encouraged me to do as much as I could.”

Another benefit of providing feedback was that it may have helped staff to focus on specific aspects of the communication and consultation approaches. This is vital because the thoughts, feelings and behaviours which comprise these processes are complex, nebulous and not always accessible to conscious awareness. Being able to refer to written material which pertained to their efforts and objectives probably enabled the staff to establish enough of a grasp in order to proceed and develop the work.

In response to the question, ‘How do you think the staff got on with the various ways I kept in touch, and provided information or feedback?’, two of the managers commented:

“Excellent. Gave staff time and opportunity to reflect on previous work. Many staff gained valuable insight into their own communication style and residents’ ideas.”
“They could see progress, and feedback was very supportive. This I feel was a big factor.”

The fact that written feedback also functioned as a stimulus to increased discussion and shared interest between staff members was pinpointed in the following:

“Accurate, and good for liaison among staff.”

**Providing reading material**

Another way of supporting staff in developing approaches to communication and consultation was to provide them with reading material. The success of this strategy seemed to depend on providing the right material at the right time, so that it would have maximum relevance to what they were doing. It also relied on staff being willing to undertake reading in their own time since finding time to read within working hours was generally impossible. However, in almost all cases the staff were grateful and enthusiastic about what I gave them. The following is a selection of the comments they made on the feedback questionnaire:

“I read [the material] we received from yourself. I found it really interesting and helpful for the job that I do.”

“Always interested in the topics. Found them relevant to the work I was trying to do.”

One of the managers said:

“Most of the staff approached reading material enthusiastically and discussed the content with colleagues/supervisors.”

This latter point is probably very important. As with other aspects of the work, it seemed that staff got most out of what they did if they had the chance to discuss their views about what they had read with someone else. There is now published a constant stream of high quality, and very practical and relevant, material on a wide range of subjects within dementia care. Supporting staff in accessing and using this must be a progressive strategy. Linking in with such resources will not only expand their knowledge, but also help staff to feel connected with the ever-widening community of people concerned with improving the care of people with dementia.
Audio recording

It was always intended that some audio recording of conversations between participants and members of staff would be undertaken. The initial idea for audio recording work was to have material which could be analysed using specialist linguistic techniques, such as discourse analysis. In the event this approach was not used, but the recording yielded so many valuable insights that it was pursued in all the sites (although not with all the participants).

The practice of recording and later examining recordings of conversations had already been undertaken and written about (for example, Hamilton, 1994; Killick, 1994; Keegan, 1998). It was expected that this would be a useful strategy in the project for several reasons:

• the words of people with dementia are often difficult to interpret, and so audio recording would provide a way of enabling me and the staff to re-hear and give closer attention to their utterances

• recording conversations provides the opportunity for staff to re-hear and reflect on their own style of communication

• for the person with dementia, re-hearing their own words might stimulate further thoughts and reflections on particular subjects

• recordings of conversations provided a form of ‘hard data’ for the project.

When the idea of staff recording their own conversations with people with dementia was first introduced their reaction was generally one of scepticism and apprehension, as the following comments from the feedback exercise illustrate:

“Apprehensive, not knowing what was expected.”

“Scary (to say the least).”

“I don’t like to hear my own voice – too self-conscious I think.”

“Hated it, and only because I thought it would benefit the residents that I gave it a try.”

They also expressed concerns about the possible negative effects of recording on the person with dementia:
“Initially I thought a tape recorder would be off-putting but in actual fact it did not bother anybody.”

These concerns were fully acknowledged and discussed, however, and despite their reservations most appreciated the potential benefits of the practice, and were willing to consider the idea.

In order to encourage the staff to try this approach to the work I made copies of Caroline Keegan’s (1998) book *Talking with Jean* available to staff. This publication describes how the author, a staff nurse in a long-term care ward, undertook recording work with Jean, one of the residents in the ward. Keegan was interested in the subject of communication with people with dementia generally, and felt that it would be useful to see if she could deepen her understanding of the residents, and also learn to enhance her awareness of her own communication style and habits. In order to do this she got permission to record a series of ordinary conversations with Jean. These arose in the context of personal care such as helping Jean to get dressed in the morning, and other activities, such as looking at magazines.

She found this exercise so illuminating, she later obtained permission to write a report about it, which the Dementia Services Development Centre (DSDC) published. The report takes the form of transcripts of a series of four short conversations, together with an introduction and Keegan’s reflections on the conversations. She pays particular attention to details and themes which were clearly present in Jean’s contributions, but which she failed to pick up during the actual exchanges. Its other main strength is that it represents a small-scale project, undertaken within the scope of normal care practice (apart, of course, from the transcription, reflection and writing work which was done in the author’s own time)

Reading *Talking with Jean* had an extremely positive effect on the staff. They could identify with the author’s situation, concerns and observations, and they were excited by the prospect of replicating her approach and deriving similar benefits with their own service users. The book was definitely a major asset to the work.

In addition to the psychological obstacles to starting out on recording work, there were practical challenges. Equipment for recording was lent by me, and in almost all cases good quality recordings were obtained, but the practicalities required to have the machine and blank tapes available, and holding the
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conversation in an appropriate location where the recorder could be used, were difficult in some cases.

A method of providing feedback on recordings was developed, which took the form of annotated transcripts. These provided detailed (but not exhaustive) accounts of conversations. When quoted, the actual words of the participants and staff were supplemented by contextual detail as the following example shows:

After a slight pause K says, “Would you like a cup of tea?”

Not every spoken word was transcribed. Some of the discussion was summarised, for example as follows:

J continues speaking, apparently telling a story about members of her family.

This material was accompanied by comments and questions which represent my reflections on details of the interaction. Producing this type of feedback was very time-consuming, but it provided a unique opportunity to reflect on the details of verbal interactions, the messages being conveyed, and the styles (both those of participants and practitioners) in which these occurred.

As the use of this approach developed, it became clear that recording conversations was a very powerful way for staff to learn about communication and develop their own practice, not only in the area of service user consultation work, but also more generally. This view was fed back by staff too:

“I think this is a useful way of analysing a conversation with a person with dementia and give you time to reflect on and make more sense of what the person was trying to say.”

“Would wholeheartedly recommend it. I found it very useful after the initial recording of hearing my own voice.”

“After the first recording the second was a lot better as I did not worry about anything and concentrated on the project.”

“I think it is an excellent way to communicate on a one-to-one basis, and you do actually forget the tape recorder is on and relax very easily.”

Again, the importance of the role of positive feedback regarding recording work was identified by one member of staff:
“I felt very conscious and intimidated at first but was reassured when I got positive feedback.”

And the potential for such information to miss the mark was also noted:

“I would have welcomed more time to chat about the recorded write-ups as I felt that there were times when some of the conversation was misinterpreted.”

Through the practice of audio recording, some of the staff identified specific aspects of the communication process which they felt they needed to modify:

“I thought I was talking too much and not allowing J to speak enough.”

“... I need to speak more clearly and slowly.”

Some of the staff expressed the view that this aspect of the work facilitated a degree of personal and professional development:

“Initially I was daunted at the prospect of recording conversations. I found it embarrassing and unnatural. However, I think that you do have to look beyond yourself and your own feelings in order to be able to achieve what you are trying to do. Once you have done this, the task becomes a lot easier and more enjoyable.”

One of the managers said:

“They have become used to the tape recording and enjoy this medium, and have grown professionally.”

However, it should be recognised that this method has important limitations as well. Having a good quality audio recording of a conversation fosters the impression of completeness, but in fact most non-verbal dimensions of the exchange are lost. The absence of this information may mean that the verbal content is ambiguous or difficult to interpret. One staff member said:

“I found it frustrating when R was smiling and nodding her head and nothing appeared on the tape.”

Some staff realised that the tape recorder was not an asset with certain people:
“Client didn’t enjoy using tape recorder. Often fell silent when it appeared.”

It is important to bear in mind that in the course of undertaking audio recording work for the project, staff were given personalised support and encouragement, and detailed written feedback. While it would still be entirely possible, and very likely beneficial, to carry on such work without such support, it would require considerable self-motivation.

**Tolerating vagueness and uncertainty**

There were many occasions when staff asked for reassurance or reminding about the objectives of the study, and it was often possible to anticipate these occasions. Indeed they occurred so regularly and with so many of the staff, that the idea emerged that the experience of vagueness or confusion, and the capacity to tolerate and work within this, rather than being an impediment to the project, was actually an extremely important part of it. It may have been that by deepening efforts to communicate the staff were becoming more sensitised to the emotional world of the person with dementia, and their experiences of confusion transferred in some way to the staff. If empathy is required for successful communication then our own experiences of vagueness and confusion have the potential to enhance our sensitivity to the feelings of others.

The capacity to tolerate such feelings and proceed with sensitive and reflective work is important for another reason, however. The care of people with dementia is by its very nature highly skilled, and must frequently give rise to situations in which the member of staff has to interpret ambiguous information. In what the ethicist Post (1995) has termed our ‘hypercognitive culture’, we normally seek to minimise or deny our feelings of confusion. We feel that we should at all times know what we are doing and why. But in certain circumstances it may be much more adaptive to remain open to such feelings. Psychologists are beginning to explore the role of intuition in learning and acting in complex situations, and it seems that the ability to tolerate confusion is a real asset (Claxton, 1998).

In communication work with people with dementia success may be most often achieved by exercising the skill of being able to maintain a state of greater openness and uncertainty in response to complex and ambiguous stimuli, many of which are not easily verbalised, and to entertain multiple possibilities for interpretation and response. Models of care which emphasise well-defined procedures and the need for evidence-based decision making may undervalue this form of relating.
Many of the ways in which I worked with staff seem to have implications for the style of support and supervision which can be provided within the workplace, as well as that which can be delivered from external agencies.

**Summary**
This chapter describes how I went about working with the staff who took part in the project. It discusses both the stages of the work and the methods used.

Communication and involvement are part of everyone's job description! The best practice and commitment to take ideas forward had to come from staff members themselves.

Good practitioners already have much of the knowledge and many of the skills needed to enhance communication and make consultation and involvement a reality. We need to find ways of helping staff to recognise and value these resources, and to use them in the most effective ways.

Although many of the staff who took part in this project did initially feel anxious and somewhat confused about the aims of the work, with reassurance and positive feedback they quickly became more confident. Towards the end many said how much they had valued and enjoyed the work.

Staff should not be left to do this type of work without support. We need to listen to and understand the anxieties that practitioners face. The challenges may seem confusing and uncertain at first, but being able to work within these realities are probably important qualities in working with people with dementia.

It can be difficult at first to generate a sense of ownership and belief in the work, and keeping up the momentum can be a challenge too. However, staff in the different sites were able to do it. An important element of this is about there being someone whose role is to help them keep focused.

Time and feedback are essential. Staff said that it was important to have these to help them learn from and develop their initiatives. It is often from reflection on an incident – rather than simply doing the task – that insights and ideas emerge.

There is a lot of relevant, accessible reading material available. Staff said that this was really helpful and gave insights into what might be possible.

In particular, many staff found audio recording conversations to be of enormous value, although initially they found this a daunting prospect.
This chapter describes a selection of the approaches to communication and consultation tried in the course of the fieldwork phase. We start with some general points, and give examples of some particular initiatives. (To protect confidentiality, names and identifying features have been changed.)

**Finding the right words**
As service providers and researchers we become used to employing certain jargon terms and shorthand descriptions. The word ‘services’ is itself a technical term, and may not have very much meaning to those outside of specialist spheres, and especially in the course of communication with people with dementia.

A direct example of this is the names people use to talk about places. In the case of one service, it was known by staff that service users would be very much less likely to attach any meaning to the name of the day unit itself, whereas the name of the hospital was familiar. On listening back to a tape-recorded conversation, one practitioner realised that she had used the word ‘residential’ in a way that was obviously not meaningful to the person with dementia, and this may have curtailed the possibility of useful discussion about the woman’s perceptions of such an option.

Finding the right words to talk about services was especially challenging in situations when it appeared the person’s understanding of their own circumstances differed markedly from that of others, for example where someone seemed to believe that they were at work while attending a day centre.

**Finding the right level**
There was also the issue of what level to focus on in talking about the person’s experience of using the service. Some discussions were framed, at least initially, at a very general level – for example, ‘What do you think of living here?’ or ‘How do you feel about coming here?’ Depending on the person’s response, such approaches could be modified or refined. If they responded in general terms, this could be developed appropriately. If they mentioned a specific aspect of the service in response to a general prompt, then the discussion could proceed along those lines.
This is related to the very important matter of how people who use services make sense of their experience of doing so. For one person living in a residential home may be dominated by the sense of loss of independence, for another the enjoyment of company and a sense of security may be much more prominent. If efforts to consult individuals about their views are to occur in an individualised and sensitive way, then they must be based on some understanding about the person’s own sense of meaning in being a service user.

With many of the participants it was necessary to find starting points for establishing opportunities for communication which did not necessarily immediately take the form of service user consultation work. Since the set of participants included many people who had significant difficulties with communication, it was important first for staff to try to establish opportunities for more general communication work which could lead to the development of ideas for more specific approaches. Despite the fact that in all cases the individual with dementia was well-known to the member of staff, it seemed important to encourage them to spend time with the person paying particular attention to communication and going along with whatever came up or seemed interesting at the time. From these beginnings it was possible to shape up more specific approaches.

**Planned and spontaneous work**

While a great deal of thought went into the work generally, some of the individual initiatives were carried out at times and in ways which had been carefully planned, and others were more spontaneous. So, for example, a member of staff may have carried out preparation work, and put aside time to spend with an individual during a particular afternoon. Sometimes these types of approaches were successful and work was done at the expected time. Often, however, for one reason or another such plans were disrupted. Perhaps the person with dementia was not well or not in the right frame of mind, or other events interfered with the arrangement.

At other times opportunities were utilised in a more spontaneous way, perhaps because a suitable interval of time became available, or the individual seemed to be in an especially amenable state of mind, or because a particular activity seemed to suggest itself as being useful or adaptable for some communication work.

We have examples of both planned and spontaneous activities working well and some being unproductive. Having attempted many different sorts of initiatives, however, it is clear that it is not helpful to think of communication and
consultation as being activities which can be scheduled into particular ‘slots’. It is rather that if staff are sensitive and creative, opportunities for work of this kind present themselves in a great variety of ways, at different times, some predictable, some not.

The approaches
Since the point of the project was to explore and develop new ways of asking people about their views of services, it could be conceptualised as an enterprise in developing special techniques. The idea of a ‘technique’, however, did not seem to fit with the spirit of the project. It implies that there is something special, different – a discrete set of skills or actions that can be used in isolation from other activities – which, once learned, is fixed and static. It also suggests that if the technique is performed accurately then success is assured, and if it is not successful then the situation is not amenable to that intervention. The notion of an ‘approach’, on the other hand, is more broad-based and flexible, and suggests the type of action which can be used with creativity, but which is closely connected with values. It implies that a greater degree of integration with ongoing activities is possible, and that its use admits the possibility of development and personalisation.

The three main categories of approaches will be described and illustrated with work from both individuals and groups:

- work with pictures
- communication during other activities
- focusing on non-verbal communication.

Work with pictures
Many different sorts of pictures were used in the course of the fieldwork. These were collected from a variety of sources, including in some cases the participant’s own possessions. Attempts were made to find pictures of people or things which were felt likely to be of particular interest to the person with dementia.

Often initially the pictures were simply used to establish a link with the person, and the staff member encouraged the person to respond in whatever way they preferred. For some this meant perhaps simply looking at the pictures without responding verbally. Sometimes participants would make brief comments about them, and some engaged very fully with the subject of the pictures, perhaps
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going on to talk at length about them. For some the pictures appeared to act as a stimulus for talking about another subject. Some participants did not respond strongly to pictures at all. This may have been due to difficulty in seeing or interpreting the picture, or because their content was not of interest.

**Pictures of people**

This was the largest category of pictures used. They were collected from a variety of sources. Some came from magazines and newspapers, some from leaflets and advertisements, others from sets of photographs produced for educational purposes. At first efforts were made to find pictures of older people, on the assumption that these would be most successful in eliciting reactions. It quickly became clear, however, that not all the participants identified with older people. In some cases people talked in such a way that it became clear that they did not see themselves as being older (apparently altered subjective age is observed quite commonly in people with dementia). In response to this, pictures of children and younger adults were also used.

With one lady, Betty, pictures of children had been discussed earlier in the conversation with her keyworker,
What can work: examples of approaches tried

Gillian. The following exchange developed out of this, although it was not directly related:

Gillian: “And do you like staying in [name of setting] now, Betty?”
Betty: “Yes, I like it now, but I didn’t like it to begin with.”
Gillian: “Did you not?”
Betty: “Because they were far too strict. You didn’t get to use your own mind. And I have a mind of my own!”

There is some talk about other matters, but a few minutes later discussion of this subject resumes:

Gillian: “Mmm hmm. And how didn’t they let you use your mind?”
Betty: “Oh, I like to use my own mind – what I think, not what other people think. I have a brain of my own. Maybe not very knowledgeable, but I wouldn’t hurt anyone. And eh ... I just know by people’s face, the way they look, the way they smile and that’s the way I know people.”
Gillian: “And do you like the people that you live in here with?”
Betty: “Yes, I like it here. I like some of the staff, and the ones I don’t like – they know!”
Gillian: “I bet you they do!”
Betty: “I just say, ‘Hop it!’ They just say, ‘Oh, I’m no’ going to speak to her!”

[both laugh]

One way of using pictures of people, including pictures of older people, was to encourage participants to talk about experiences of services in an indirect way. Instead of asking, ‘What do you think about living here at...?’, staff used the pictures to encourage participants to speculate on what they thought the person in the picture might think or feel. For example, they did this by asking, ‘If this
lady was going to come and live here, what do you think she would want to know about it?’, or, ‘Let’s imagine that this lady is living here, what do you think she would be thinking about?’.

A specific example of this approach was an occasion when a member of staff had helped one participant to have a bath in the new Parker bath the home had recently acquired. On the basis of her behavioural reactions the staff member was sure that the lady had not enjoyed the experience, but when she was asked directly about how she had felt, she assured her keyworker that it had been fine. The member of staff then showed the participant a picture of an older lady, and also photographs of both types of bath in the home, and asked what she thought the lady in the picture would feel about having a bath in the Parker bath. Without any hesitation, the participant replied that the woman in the picture would prefer the normal bath. When asked again a few days later, she gave the same response, and added that she herself would prefer the normal bath as well.
As mentioned earlier, in the course of attempting consultation work, it is important to try to find out about the particular aspects of the service which are most significant or meaningful to the person. The following excerpt from a recorded conversation demonstrates how this was done in one case. The preceding conversation had centred around the perception of the person with dementia, Ella, of the lady in one of the photographs. Her keyworker, Sheila, then moved into using a third person approach:

Sheila: “Now, she won’t be coming here...”

Ella: “No, no – I know that – aye.”

Sheila: “But if you was to say to her about here...”

Ella: “About it?”

Sheila: “What would you tell her?”

Ella: Well, I would ask her if she would like to come and ... em ... meet folk, and....”

Sheila: “Mmm hmm?”

Ella: “And the crocheting and things like that.”

Sheila: “Uh huh?”

Ella: “Makes an awful difference!”

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This example seems to be a very clear-cut instance of how pictures can be used as part of service user consultation. In most other cases, however, responses were not so direct.

This was particularly true of occasions when looking at pictures prompted the person with dementia to tell a story. With some participants episodes of storytelling were animated and evidently enjoyable to the person. Although in many cases this did not constitute such a direct opportunity for discussions about experiences of services, with sensitive listening and interpretation (often from audio recordings of these conversations) there were many points of interest. For example, in some stories there was strong emotional content. If a participant told a story which seemed to include her expressing anger, this could prompt reflection about whether the person was experiencing anger in the service setting, and what this might relate to.

From some stories it became clear that the person was experiencing an alternative ‘frame’ for the situation, for example apparently believing that they were at school or at work, rather than attending a day centre. At other times careful attention to stories revealed ways in which the person expressed opinions or preferences. For instance, in the course of telling one story a lady seemed to express an opinion of something by saying it was ‘first class’. Her keyworker immediately picked up on this expression, asking her, “How would you rate us, Meg? Would we be first class or would we be second class?” Meg replied immediately, “Oh, first class!”, demonstrating her understanding of the question.

Pictures of people were also used as a stimulus to conversation in group discussions. In some of these photographs were used along with short vignettes which staff composed. For example, alongside a picture of a man walking along a street in the snow there was a vignette which read:

Albert lives alone. He has to go out in all weathers to do his shopping. He likes to do things for himself.

The content of this and the other vignettes were written with the preferences and lifestyles of the participants in mind, and led to discussions in which the people in the group were able to talk about their experiences of using services. For example, here is the staff member, Linda, talking to a participant, Arthur:

Linda: “So you’re a bit like Albert, then? You like to do things for yourself?”
What can work: examples of approaches tried

Arthur: “Mmm.”

Linda: “You like to do things on your own?”

Arthur: “Yeah.”

Linda: “You don’t like to ask others for help?”

Arthur: “That’s right, yeah.”

Linda: “You prefer to struggle on....”

Arthur: “Yeah.”

Linda: “... alone, rather than ask for help?”

Here another member of staff, Jane, joins in the exchange:

Jane: “Yeah, he likes to do....”

Arthur: [unclear]

Jane: “It doesn’t matter whether it’s snowing or not, he likes to go out and get his own shopping.”

At this point another participant, Bob, contributes:

Bob: “Yeah.”

Jane: “Sometimes he does need to have a bit of a help, though.”

Arthur: “That’s right, yeah.”

Jane: “But if he can, he likes to do it for himself.”

Arthur: “Mmmm.”

[Pause]

Jane: “It’s hard if the weather’s very bad, isn’t it?”
Bob: “I like to [unclear] myself – go where I like, and please myself.”

[Pause]

Linda: “Bob, do you go out in any weather? Like Albert – would you go out if it was raining, snowing...?”

Bob: “It doesn’t bother me.”

Linda: “It doesn’t bother you? I know you prefer it if here, don’t you, during the day if I can take you out for a walk in the afternoon?”

Bob: “Oh yeah!”

Linda: “You like that don’t you? We’ve been trying to do that more often, haven’t we?”

Arthur: “Mmmm.”

Linda: “I know you like your fresh air.”

Here Arthur joins in again:

Arthur: “Yeah. That’s the same as us.”

Jane: “Yeah?”

Arthur: “I’m on my own, and I’ve got to go out and do shopping on my own. If Dorothy [relative] come on a Saturday....”

Jane: “Yes.”

Arthur: “And they take me out to get quite a bit of my shopping, and don’t have to go again.”

Jane: “Yes – so your main shopping? Mmm hmm. Do you like to keep doing your own shopping?”

Arthur: “Mmm, I do, love. Yeah.”
What can work: examples of approaches tried

Jane: “Why’s that?”

Arthur: “What ... Dorothy?”

Jane: “No, why do you like to do your own shopping?”

Arthur: “Well, I do ... ‘cos I know what I want. That’s the reason.”

Jane: “Yeah?”

Arthur: “I know exactly what I want and what I don’t want, and one thing and another....”

Jane: “Yeah.”

In one group session, discussion focused on a particular part of the day – arriving at the day centre in the morning. Again in order to stimulate ideas, reference was made to a photograph of an older woman. Wendy and Alison are the members of staff, Nancy and Rosie the participants:

Wendy: “So you think she would feel welcome when she arrives?”

[Murmurs of agreement]

Wendy: “Do you feel happy coming in? Do you feel that you’re made welcome?”

Nancy: “Yes. I like to be....”

Alison: “Who makes you feel welcome, Nancy? How would you [unclear] make you feel welcome?”

Nancy: “Well, they’re very friendly, and they’ll speak to you.... That’s my view.”

Alison: “Right, so you want someone to say ‘hello’ and speak to you to make you feel welcome – that kind of thing?”

Nancy: “Yes.”
Alison: “What about you, Rosie?”

Rosie: “Much about the same as Nancy was saying. Meeting other people, talking.”

In the case of one participant, work with photographs of unknown individuals was replaced by using a picture of the lady’s mother as a stimulus to conversation. The member of staff would look at the photograph and they would talk about her mother. Then specific questions were formed by asking the lady what she thought her mother would have made of aspects of the service. On one occasion a member of staff, Wilma, used this approach with Peggy. It elicited an especially emphatic response, and the conversation went on to develop with Peggy talking more directly about herself, as the following excerpt illustrates:

Wilma: “What would your mother have thought of you staying here?”

Peggy: “Oh, she would – Oh aye! If she thought they were shoving me into a hovel, she would have come up and had a look herself and if it didn’t suit her, she would say, ‘She’s not going in there. She’ll just have to go back into her community’, but [unclear]. But I haven’t had to do that ‘cos they’ve been awful decent to me.”


Peggy: “Aye! Very happy!”

Wilma: “And do you like your room?”

Peggy: “Yes!”

Wilma: “Aye?”

Peggy: “And I can please myself – nobody interferes with me. Not that I do anything that needs [unclear]. D’you know what I mean?”

Wilma: “Mmm”

Peggy: “When you feel free that’s when you don’t use your freedom.”

Wilma: “Mmm hmm.”
Peggy: “It’s when you’re tied down, and everybody says, ‘You’ve this to
do, you’ve that’, but it’s just ... sort of ... get in ... and just....”

Wilma: “What do you like about your room, Peggy?”

Peggy: “What do I like about it?”

Wilma: “Aye.”

Peggy: “Aye, [unclear] it’s fine [unclear] my head.”

Wilma: “Mmm.”

Peggy: “[unclear] my own bedroom.”

Wilma: “And what do you not like about it?”

Peggy: “Well, I can’t say there’s anything [unclear].”

Wilma: “Not anything?”

Peggy: “No! Everything is there. And the drawers are there.”

[Sound of drawers being opened]

Peggy: “Well ... happy here.”

Wilma: “Are you happy here?”

Peggy: “Aye.”

Wilma: “Well, will we go down and get a cup of tea?”

Peggy: “Yes.”

During conversations like this a great deal of information, both about the
participant’s previous history and lifestyle, and also her feelings about aspects of
current life in residential care were communicated, and always in a way that
respected and supported her own way of expressing herself.
For some people it appeared that the activity of looking at pictures, and commenting on them, acted as a way of helping them to relax and lose what may be a degree of self-consciousness about their ability to express ideas and feelings. This may have been true of the staff members as well. While we recognise that for people with dementia the effort of expressing themselves can be painful, frustrating and anxiety-provoking, we should also recognise that for staff the activity can also be difficult. This issue is explored further in Chapter 5 on the challenges inherent in the work.

**Pictures of objects**

Pictures of objects, such as items of food or household furniture or utensils, were also used as starting points for discussions. Again sometimes responses were quite immediate. One participant, on looking at pictures of games of various sorts, commented on how much she used to enjoy playing dominoes. This was new information to her keyworker, who was then able to talk to her about possibilities for incorporating this activity into her normal routine.

Some responses to pictures were much less predictable. The same lady who commented on the dominoes misperceived a picture of a coal scuttle and stove for a little girl watching television. This led to a discussion about whether the lady would like to have her own television, and as a result of this a hi-fi was bought which she very much enjoyed using.

Sometimes pictures were used in a much less focused way, with the aim of establishing the habit of the participant and member of staff spending time together, establishing a routine for communication work, and focusing on the person’s views and opinions in a general manner. A set of pictures of flowers of different colours was made for one participant, both because she was known to be highly sensitive to colour and also she had been a keen gardener. Time was spent with her looking at the pictures, and asking her preferences in terms of the colours and flowers. This provided an opportunity, not only to establish positive communication, but also for the member of staff to observe her style of expressing views.
What can work: examples of approaches tried
and preferences. There might also have been a more indirect effect of communicating to the woman with dementia that her preferences and opinions were important and of interest to staff.

Several interesting conversations about food and mealtime preferences were stimulated by showing participants pictures of different foods. This took place on both a one-to-one and group basis.

**Other visual stimuli**

Cards with single words printed on them were also used as a stimulus to conversation about various subjects. In some cases the words were names of emotions such as ‘happy’, ‘bored’, ‘sad’, ‘irritated’, ‘relieved’ and so on. These were used during one of the later sessions in one of the group initiatives. One member of staff laid out the words on the table and then said to the participant, “We just wondered which word would fit most how you felt about coming to this place”. This drew a fairly immediate response from participants, one of whom pointed to the card with the word ‘bored’ on it. It would only be fair to say that staff were already aware of this participant’s feelings about this subject, but the discussion went on and included strong emotional expressions about other services the person had used. Another function of having the emotion words visible may have been to facilitate conversations again of an indirect nature, where people can talk about the possibility of having certain feelings without necessarily having to admit to them directly. The following excerpt may be an example of this:

Abi: “How do you feel about coming here? When you come up? When the bus brings you up for the day?”

Elsie: [Sounding surprised] “I don’t feel anything at all!”

Abi: “No?”

Elsie: “No.”

Abi: “Do you like company or ... do you prefer...?”

Elsie: “Yes. Yes, I do. I’m not scared.”

Abi: “No. Good.”

Elsie: “And I’m not lost either.”

Abi: “Good. Do you ever get a bit...?”

Elsie: “Confused? Well, not in those ... no, not in those. Could be relieved.”

Abi: “Relieved?”

Elsie: “If I was in a bit of a ... stew ... [laughs].”

Abi: “Right, so you could feel a bit relieved sometimes...?”

Elsie: “Could be. I’m not saying it is.”

Abi: “No.”

The emotion word cards were used on an individual basis with one lady who enjoyed doing word games and activities such as completing proverbs. As an extension to this, I provided sets of questions on various subjects, some of them general, some of them related to service issues, together with a set of words on cards which were possible responses to the questions. Some of the questions were designed to touch on subjects which were known to be of concern to her. Following on from the more familiar activity with the proverbs, which served as a ‘warm-up’, a member of staff tried out the new questions with her. This worked very well, and some of the lady’s answers seemed clearly to indicate her feelings on particular issues, and her preferences in various situations.

The original idea for using the word cards was to provide information that people with dementia could respond to, rather than having them forced to try to answer questions or express themselves using words they had to find themselves. In this situation it was not clear whether the participants would have been able to come
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up with words themselves to express their feelings, but it definitely seemed that having the words easily visible helped to promote the fluency of the conversation. Another possible function of having the emotion words visible may have been to give a tacit acknowledgment of the possibility of participants having certain feelings, and thereby making it easier for people to admit that they did experience them.

Communication and consultation as part of another activity

It was recognised that for some people an exclusive focus on talking was not helpful or may even have been inhibiting, and that combining opportunities for conversation with other activities might provide useful starting points. Activities of various sorts were explored.

Personal care

For many people it seems that times devoted to personal care – being helped to get up or go to bed, bathing, hairdressing, and so on – provide opportunities for communication which is more in-depth than at other times of the day. In the course of undertaking initial discussions with staff about possible times to focus their efforts these occasions were mentioned quite often. This may be because the situation is private, regular and takes a certain amount of time allowing the person to try to express their thoughts and feelings. If the person with dementia enjoys, say, having a bath, then the sense of relaxation which accompanies the experience is likely to enhance communication. Efforts were made, therefore, to capitalise on these occasions. There were several instances when this seemed very successful, and a level of communication occurred which was not in evidence at other times.

On one occasion with one participant whose verbal communication was normally difficult to interpret, but who normally seemed to enjoy having a bath, staff made an effort to help him to relax even more than usual, and more time was taken over the activity. The member of staff was very struck by how much more communicative the participant was – talking and laughing more than usual – and although much of what he said was still difficult to interpret, she felt sure that a regular opportunity such as this would result in a significant enhancement in communication, helping him to express his thoughts and feelings.

Going for a walk

In most cases conversations or other sorts of communication about aspects of services took place within the care setting. In one lady’s case, however, her keyworker was keen to try talking to her while out on a walk. She knew that
walking had been a longstanding and favourite activity, and felt that she may have been able to express herself more easily in this context. The conversation which took place on the walk was preceded by a similar one several days earlier in the home. On the first occasion the lady was able to express herself, but she was fairly halting and seemed to lack confidence. However, on the second occasion, while the lady and her keyworker were walking near the home, she was able to express herself with much more fluency and confidence, and say more about subjects which had only been touched on briefly prior to this. It may have been that being away from the home freed her to speak more frankly, or that earlier in her life walking as an activity had been accompanied by thinking, so that this well-established habit supported her in her efforts to communicate important thoughts and feelings.

**Food tasting**

In one of the group sessions this activity was used very successfully. Various sorts of food were provided, and participants were encouraged to try them out and talk about what they liked and disliked. This type of activity had the advantage that it was directly about the subject of preferences, but about a relatively non-threatening subject. In this particular setting talk very quickly moved into a reminiscence-type activity with people remembering and relating food-related anecdotes from their past, and talking about local expressions for different fruits. On this occasion the talk did not develop in the direction of views about services, but it was clear that it had the potential to do so.

**Non-verbal communication**

Throughout the planning and preparation stages the importance of approaches to communication and consultation which did not rely on words was repeatedly emphasised. During the phase of planning the fieldwork and coming up with ideas for approaches (see Chapter 4) there were many conversations with staff about communication which took a non-verbal form. The staff were clearly very aware of the importance of this type of interpersonal behaviour, both in terms of what the person with dementia expressed and also in terms of their own approach and style of presentation and communication. But non-verbal communication is, by its very nature, difficult to talk about, and many of these conversations grappled with the challenge of giving verbal shape to the kind of very complex, fleeting and subtle looks and expressions, and gestures and actions, which constitute non-verbal communication. It was recognised in many of the settings that particular members of staff were especially able to communicate with certain service users, although attempts to analyse exactly what was different about their approach often eluded us.
The inherent complexity of non-verbal communication posed significant challenges to attempts to focus on and describe particular aspects, and the fact that it is a continuous process (at least while a person is awake and conscious), meant that it was difficult to find a point at which observation and recording should start and finish.

For all of these reasons work looking specifically at non-verbal forms of consultation occurred later in the fieldwork phase. With some participants, efforts to engage on a verbal level had not proved successful and a shift to thinking in more non-verbal terms was made; for others staff set out with a non-verbal focus in mind from the beginning.

In common with the other sorts of approaches, encouragement at first was given to finding ways for staff to raise their awareness of non-verbal channels of communication generally, and through doing so to identify more specific focuses for further work.

The approach which most staff used at first was to identify times of the day (or night) when they felt that the participant was experiencing something specific, whether this was a physical state such as pain or needing to go to the toilet, or a particular frame of mind, such as anxiety, pleasure or anger. They were then asked to complete a form which had been designed by me for the purpose. This asked the member of staff to write about details of the situation, events just prior to the period of observation, notes on particular aspects of non-verbal communication, and also their own interpretations and reactions to the behaviour. In many ways this seemed a very simplistic approach to exploring such a complex phenomenon, but in several cases it developed very interestingly.

In one lady's case, her keyworker completed eight such forms, all in different situations. At first she looked out for things which were happening anyway, and wrote her notes. This led to what the staff member described as a significant increase in her level of sensitivity to the lady's non-verbal communication generally. There then followed a couple of occasions when it was clear that the lady expressed preferences and in ways that were only evident on especially close observation.

For example, at a mealtime when the constituents of her main course where being served to her while she was seated at the dining-table, she expressed pleasurable anticipation at everything which was put onto her plate – fish, potatoes, vegetables – until some parsley sauce was poured over her food. At this
the expression on her face changed completely, and, unusually, she actually said the words, “Don’t like”. Staff immediately responded by asking her if she would prefer her meal without sauce, to which she replied clearly that she would. This was a very well-defined instance of her preference having been noted and acted upon, and staff were convinced that it led to her expressing more preferences, and more clearly, than she had before. Staff were delighted at this heightened level of engagement, and became even more attuned to her style of expression and interaction. There were more instances where choices were indicated and honoured, and what seemed to be a very positive cycle developed and has continued to flourish.

The fact that this enhancement was possible within a well-established relationship, and where staff were already clearly committed to person-centred care, indicates that there is a lot of scope for very useful and satisfying work.

In many ways the possibilities for more work on non-verbal communication were curtailed by limitations in the length of the fieldwork phase, particularly as the initial difficulty in finding starting points meant that we had a late start. The response of staff to focusing on this dimension of communication was extremely positive, however, and was an especially good example of how radically the perception of staff of individual service users and the experience of providing care for them can be altered by apparently simple and small-scale interventions.

Work on the area of non-verbal communication also highlighted the importance of intuitive responses in the care of people with dementia, and the need for staff to be encouraged to respect their own judgement and skills, especially as regards very fleeting and ambiguous communicative cues. This is a topic which requires much more exploration.

Of course, all of these initiatives took place in the context of many, often competing, demands for staff time and attention. How these challenges were met is the subject of the next chapter.

**Summary**

This chapter provides an overview of the types of approaches used, together with illustrations and excerpts of dialogue/group discussion.

There are challenges to be faced in finding the most appropriate starting points – for example, how specifically to focus on the person’s experience of services, and what sort of ‘frame’ is most meaningful to them.
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Some of the work was carried out according to plans the staff member had already made. Other initiatives were undertaken in a more spontaneous manner.

Visual stimuli, such as pictures, were used with many of the participants. Various sorts of pictures were used, and they were employed in a variety of ways. The most successful approaches seemed to be those which allowed the person with dementia maximum control over how they interpreted material and what was said.

For some people communication and consultation work which took place alongside another activity, such as personal care or going for a walk, was most successful.

From the outset we maintained a focus on the non-verbal ways that people used to express preferences and needs. On account of its subtlety and complexity, it was more challenging to find ways to explore this mode of communication. However, many of the initiatives which were undertaken in this area proved highly successful and staff became very interested in the subject.

The most important message is that we need to aim for the right ‘state of mind’. Once you accept that it’s not simply about techniques or which tool will work, then there is a wide range of everyday activities that are rich in the possibilities of communication, and thereby of involvement.

Although getting started on finding ways to communicate with people and promote their involvement can be difficult, it is important not to think of these activities as ‘rocket science’. As these examples demonstrate, it is about creating opportunities for people to bring to bear those very human processes and qualities that we all value and appreciate in our relationships.
While convinced of the many possibilities for developing meaningful approaches to consultation work with people with dementia, we need to recognise that there are many challenges too. This chapter is devoted to describing how these may operate in services generally, again providing illustrations from the project work. The purpose of this is not to overwhelm the reader with the sheer difficulty of the undertaking, but rather to set the work in the context of real service settings, with all their complexity and unpredictability.

For the purposes of discussion, the overall set of challenges will be divided up into:

- factors pertaining to the person with dementia
- those arising from characteristics of individual situations
- factors pertaining to the member of staff
- those which are connected with organisational features of a particular service.

Of course these separations are somewhat artificial. In any given situation, often more than one influence will be operating and they interact in complex ways.

**Factors pertaining to the person with dementia**

Like anyone else, people with dementia experience variations in their moods and preoccupations, abilities and interests, and inclinations to participate in activities. When the more enduring and fluctuating features of dementia are added, it is clear that there are challenges in finding the right opportunity to undertake a specific piece of work.

Dementia aside, however, people differ from one another in their personality, style and dispositions. Some find talking and expressing feelings and opinions natural, others are much less inclined to share themselves in this way. Some people need little encouragement to engage in discussion, while for others this would be an activity requiring careful consideration and preparation. The fact of their developing dementia may or may not have altered the individual’s
dispositions. Sometimes we discover that a person who has been reserved and cautious in life prior to dementia becomes much more forthright and open in the context of the condition, while others seem to lose confidence regarding the expression of views and opinions. Any attempt to engage with a person in undertaking communication and consultation work must obviously take account of these characteristics, and respect the person’s wishes. Those who do not respond to the more conventional types of approach will challenge staff to think of alternative and more acceptable ways for the person to express their needs and preferences.

As mentioned earlier, staff often observed that over and above basic personality dispositions people with dementia seemed to experience fluctuations in the extent to which they were able to enjoy company, engage in communication with others, and become involved in activities, and that this variability expressed itself on a minute-to-minute and hour-to-hour basis. Sometimes there were clear daily rhythms with, for example, late morning generally being a stronger time than early afternoon. These patterns may be related to psychological factors such as mood or confidence, or they may be based on physical influences, such as energy level, or the presence or absence of pain. Features of the dementia itself may account for some of the variability, or it may be linked with environmental influences (discussed further below). It is also likely that the patterns we observe are based on a complex interaction of all the above sets of factors.

Where there does seem to be variability in the level at which the person is able to function, it would obviously make sense for efforts to coincide with times when the person seems more able to express themselves and make most sense of the speech and actions of others. Indeed these sorts of patterns often featured in the discussions I had with members of staff regarding the development of individualised approaches.

In busy services where staff resources are stretched, however, this can be a major challenge. In work for the project, it quite often happened that if a particular individual seemed most able in the late morning, and their keyworker only worked part-time, then it was likely that they were in for an early shift only once or twice per week. This means that even in 24-hour services such as residential care, the actual amount of time the person with dementia and their keyworker can spend together and devote to communication is limited to a maximum of two or three hours per week. Nevertheless if this could be achieved on a regular basis, it would be very valuable, but as we shall see there are a host of other influences which have the potential to interfere.
Situational factors

On some occasions it appeared that a particular approach worked well, perhaps resulting in the expression of ideas and views which were either new to the member of staff or were put across in a novel way, while at another time a similar approach with the same person did not achieve comparable results. As well as individual differences, such variation was probably due a variety of situational factors. Here we need to bear in mind that we all are psychologically disposed to attribute the causes of events to characteristics of individuals rather than to features of situations, but that often the reality is more complex.

In common with us all, but probably to an even greater extent, the capacities of people with dementia and the ways they present and express themselves are affected by environmental factors. The general category of environmental factors can be further divided into those which are physical, social and temporal.

Considering features of the physical environment first, we can appreciate that, for example, surroundings which are noisy and stuffy may impair the performance of anyone, but for a person with dementia such conditions could make the difference between them being able or unable to engage at all with an opportunity for genuine communication. The constraints in terms of space and the quality of the environment are a major factor for many services. Opportunities for privacy may be extremely limited, and arrangements may mean that who is doing what at any one time may be too obvious to be desirable.

With some of the project participants, despite constraints, considerable efforts were made to attempt work in surroundings which were relaxing and reassuring to the person, such as their own bedroom or outdoors. Recognising that positive aspects of the environment can contribute in important ways to helping the person to function at their best level, staff who ran one of the group initiatives went to lengths to adapt the space they had available for a group session so that it was welcoming, and also memorable. Having distinctive sensory cues from week to week (for example a special table cloth, flowers and scented oil) may have helped the participants to relax more readily and through associative memory form a sense of the distinctiveness of group sessions from the remainder of the daily and weekly routine.

Characteristics of the social environment which are very likely to bear on the outcome of any one approach include general ones such as the extent to which the person feels comfortable with and accepted by others, and safe about the possibility of difficulty or failure. More specifically, the behaviour of others – for
example, whether they allow enough time for the individual to gather their thoughts and express ideas, and whether they respond appropriately to communicative cues offered – are bound to have a significant influence on the experience and outcome of an encounter. Again such influences have a powerful effect on all of us, but for the individual with dementia their impact is likely to be even greater.

Temporal factors, such as the timing of an approach and the effect of foregoing activities or events are also likely to be important. Those of us without dementia vary in the ease with which we can move from one activity to another, and the extent to which preceding events affect our subsequent performance. For the individual with dementia the feelings generated by, say, a visit from a relative or a necessary medical or nursing procedure, may have a very significant effect on their capacity to engage with an opportunity for communication work, even if others are able and willing to try something at such a time.

The reality of all of these factors means that if we are to adopt truly person-centred values as regards communication and consultation work, we need to take them into account in making decisions about what sort of approach might be most helpful, when and where this is attempted, and in what kind of combination with other events and activities. Given the complexity of individual people, their condition, and the interaction between them, we are operating in a set of highly differentiated and complicated situations, which will certainly stretch our ability to respond.

**Staff factors**

The recognition of the person within dementia has recently begun to foster the realisation that staff are people too, however much organisations and systems may be disposed to treat them like tools. If we are fully to explore the potential of communication and consultation in the world of services for people with dementia we must recognise that staff are complex and vulnerable human beings who bring not only considerable sensitivity and intuition, knowledge and skills to their work, but also limitations, blindspots and negative habits.

Issues pertaining to staff as an influence on work undertaken can again be divided up into subcategories:

**Attitudes and behaviour**

A person’s basic outlook – the set of assumptions we develop and carry with us through life – has a major influence on how we make sense of and behave in
individual situations. If, for instance, someone believes that dementia completely destroys the person within the body, then attempts at real communication will be seen to be irrelevant. If there is a conviction that people with dementia are inherently vulnerable and require protection and nurturing in all situations, then providing opportunities for making choices, and even allowing the person to make mistakes, are likely to be curtailed.

Work with people with dementia is by its very nature deeply challenging, often pointing up the shallowness and inconsistency of our beliefs, not only about the condition itself, but also what it means to be a human being in relationships with others.

Sometimes this means that it is easier for staff to distance themselves from this reality by adopting a more practical focus, for example emphasising and responding to the individual’s physical needs at the expense of engaging at an emotional or spiritual level. Such a disposition is clearly not helpful for efforts to establish practice based on real involvement of the service users, but credible approaches to practice development must acknowledge and accommodate these realities.

However, it is also unreasonable to expect staff to start out with the ‘correct’ set of attitudes. We are all ‘feeling the way’, and what seems to be the most important thing is creating an atmosphere in which staff can try things out and learn from their efforts, at the same time tolerating the experience of complexity and confusion described in Chapter 3. (Although obviously all exploration has to proceed with respect for the individual with dementia and concern for their welfare to the fore.) This value was made explicit at the outset, when it was emphasised that in the project there were no ‘experts’ (and this included me).

**Self-esteem and confidence**

These qualities have a huge bearing on all the things we do from day to day, and especially on those which are new and unfamiliar. As has been detailed already, the experience of anxiety and apprehension among practitioners at the prospect of becoming involved in the work and trying out new approaches was almost universal. This probably related both to the individual staff member’s perceptions of their own skills and knowledge, and also the prospect of exposing their practice to scrutiny, especially by an outsider. The practice of making audio recordings of conversations was a very specific example of this. There was also the fact that the aim of the project was to encourage people with dementia to express views about services – in effect to give feedback about the success or otherwise of the efforts of those undertaking the work. In addition to all of the
above, in many ways the open-endedness of the work we were undertaking meant that in trying out particular approaches staff were being asked to take a step into what may have seemed like thin air, essentially to take a risk.

The justification for feelings of anxiety among staff was therefore ample. Although some of this was attributable to the fact that they were taking part in a special project, many of the factors would pertain in any service situation and must be considered as part of the whole enterprise.

**Personality factors**

Just as we now recognise the importance of personality factors in the way the individual copes with their dementia, we are also in a better position to consider these influences in members of staff, and how they relate to service users. In one of the project sites in particular there was a lot of fascinating discussion about how the degree of the compatibility of the personalities of the member of staff and the people with dementia contributed to the success or otherwise of specific approaches and encounters. It was recognised that where two people have a similar general outlook and disposition there can be a quality of understanding and empathy which transforms the potential for in-depth communication. Whereas a quiet, low-key approach which reflects the personal style of one member of staff may suit one person very well, enabling them to express important ideas and feelings, it may be completely lost on another who finds it easier to engage with a member of staff who projects themselves more forcefully. It may also be that the individual with dementia will relate more successfully to members of staff with different personalities at different times, or in a way which varies with the progression of their condition.

If services are to make the best use of the resources at their disposal it seems important to acknowledge and work with the different qualities the members of a team can offer.

**Relationships with individual service users**

Individual members of staff will find it easier to relate to some people than others. It is not realistic to expect workers to be able to get on with everyone, and working with the natural affinities between individuals seems sensible. Of course, problems can arise where services have particular users who are not attractive to anyone, whether through personality, or current or past behaviour. Work with people who challenge services in this way often prompts the development of very innovative, inspiring practice. Development in the area of service user consultation needs to draw on all the creative resources we have.
Variability in the wellbeing of staff

Just as people with dementia have good days and bad, so do practitioners. The same patterns of variability in energy, attitude, confidence and creativity apply to them, whether this arises from influences within the workplace or related to mental and physical health, or personal circumstances.

And since all work with people with dementia demands sensitivity and judgement and the ability to adapt to fluid and complex situations, we can appreciate that, when novel demands such as the effort to develop approaches to consultation work are added in, the load is considerable. Staff need to be helped to support one another in terms of generating ideas, giving feedback and taking the next step. Having resources to hand which provide suggestions and materials for starting points is obviously important too. (As mentioned earlier, a major outcome of this work will be a set of training/development materials aimed at managers and staff, to be published by the DSDC.)

We talk a lot about the cognitive limitations of people with dementia, but again it is crucial to recognise and work within our own limitations. Even when opportunities for undertaking work do arise, staff are fallible human beings who cannot always achieve a particular quality of focus and emotional readiness, especially to do something which is subtle and demanding. The fact that often opportunities need to be combined with keeping one eye on the clock and an ear out for signs of need or distress from the others in one’s care, only increases the level of the demands.

However, our experience in the project was that although finding the time and energy to undertake a specific piece of work could be challenging, staff often found the response from the person with dementia extremely interesting, and what they learned from the encounter had the effect of enhancing, at times even transforming, the quality of their relationship with the individual. To this extent the investment of what seemed to be a small amount of effort could have disproportionately positive results.

Illness and other absence

Staff absence, whether due to illness or other reasons, was a factor in some of the settings which took part in the research. Although obviously unavoidable, it did have an impact on what it was possible to achieve in the time available, and where staff absence was combined with fluctuations in the health of the person with dementia and the various situational and organisational factors, the limitations imposed on what was achievable were very considerable. The absence of familiar and valued members of staff clearly also had an impact on individual service users.
and their opportunities for communication, sometimes leading to a loss of confidence where this had derived from a degree of consistency of approach.

During the period of the study several of the participating staff also left their employment, whether to take up other jobs, attend courses or for other reasons. We should recognise that although the departure of individual members of staff is normal in a working environment, this can constitute a very real loss to people with dementia.

Although staff absence and turnover is associated with many factors, it is often noted in services generally that there is a relationship between these indicators and feelings of stress in staff, and also certain features of management and organisational style. This is a challenge which faces all services, but again it is likely that such indicators are mediated by staff morale. Anything which has a positive impact on the day-to-day experience of the job, the quality of relationships with service users, colleagues and managers, and the overall sense of meaning staff have in their work, must be of fundamental importance. The subject of the current project is of central relevance here.

Organisational factors
Service settings have to deploy limited resources to meet multiple, sometimes competing demands. Even highly progressive services, which are committed to upholding the personhood and dignity of their users, frequently struggle to adapt themselves and their practice to be in line with these values. Many different factors were encountered in the course of the project work.

General ethos of the organisation
The services which contributed to the project were identified and selected on the basis of their interest and motivation, so difficulties such as negative managerial attitudes were not an issue. However, it is important to acknowledge that, in general, the attitude of managers regarding, for example, person-centredness as opposed to task-centredness, is crucial. Staff who do not feel supported in developing their own ideas and approaches but instead are steered towards adhering to defined procedures and routines, will not only feel stressed, but will ultimately be unable to undertake innovative work.

Staffing levels and pressure on personnel
This is an issue for almost all services, and it was certainly a challenge for staff who contributed to the project. It was always an effort to set aside the time and devote energy to communication and consultation initiatives.
However, in thinking about the issue of pressure on time, both actual and perceived ‘busyness’ should be considered. Sometimes members of staff who feel the most busy are those who lack confidence in their skills and knowledge, or who are oriented towards completing tasks at the expense of engaging with individuals.

**Diversity of the user group**
This is an issue which varied from service to service, but it was certainly a subject of discussion with many members of staff who took part in the project. Some of the challenges inherent in developing approaches to communication arose out of the variability in the characteristics of different individuals, and also the situations which could arise when people with very different strengths and needs interacted with one another. Responding sensitively to this kind of diversity, especially in group situations, demands great skill.

**Effect of routines and other activities**
As discussed earlier, an important influence for many people with dementia is the time of day (or night) when an approach is made, and how it is related to other activities. Service settings which are organised to meet the needs of many people obviously must have routines of some kind, but there is a tension in the extent to which routines can be adapted or stretched to address the requirements of individuals. Models of person-centred care stress how essential it is that services are needs-led as opposed to staff- or systems-led, but rehearsing the rhetoric is easier than making it work in practice.

The staff who contributed to the study on occasion went to great lengths to fit opportunities for individual or group work into the usual routine, sometimes missing breaks, staying late or even rearranging days off to do so. Time for reflection, writing and reading was sometimes found during off-duty hours. While they of course deserve credit for their commitment, services cannot rely on this level of individual dedication.

**Limitations imposed by shift systems**
Getting to grips with the complexity of shift systems worked by staff posed a major challenge for me, and also emerged as one of the main organisational influences in opportunities to undertake work. Fluctuations in the health and wellbeing of the person with dementia, as well as the variability in their capacity to engage with particular approaches, combined with the number and distribution of hours worked by staff, often meant that long periods of time could go by (for example three or four days) without any real opportunities for contact with those staff members who knew them well. This was particularly acute for
staff who worked part-time, and whose hours were arranged around especially busy periods in the day-to-day pattern of the service.

Certain sorts of shift patterns heightened this problem. Staff on ‘rolling’ shift arrangements (where they went through a fixed cycle of early, late and night shifts) were only able to spend time with a particular resident at a particular time of day once in every six weeks. This posed obvious difficulties for attempts to promote routine and continuity in aspects of care.

**Impact of staff sickness, holidays and other leave**

We have already mentioned the impact of staff absence on individuals, but the consequences of this at a more general level need to be considered as well. In the case of a residential service, for example, and in the smaller units in particular, the absence of a regular member of staff frequently meant that staff from elsewhere in the home or even ‘bank’ staff came into the unit to help out. These arrangements often necessitated established members of staff altering their pattern of duties either to deal with particular jobs or to support the less experienced person in working with residents. This acted further to curtail opportunities for working in special ways with individuals.

All the above factors, and the ways in which they interact, clearly have relevance not only for particular projects such as the present study, but also for the quality of care generally, and the place of communication and consultation within it. Since the aim of the project was to explore the reality of undertaking this sort of work in ordinary service settings, the context of the efforts undertaken was of prime interest.

**Summary**

This chapter describes the many challenges the staff who took part faced in trying to carry out the work of developing approaches to consultation.

Because the style of the research was to stay as close as possible to the reality of ordinary service settings, this material is of major relevance to efforts to incorporate service user consultation work into the provision of services.

There is no clear ‘map’ of all the possibilities and barriers in every organisation. For some, the physical environment will be an important one to be negotiated. For others, it will be the social environment of the service setting. It is more about being clear in identifying the specific possibilities and barriers, and then looking for strategies to address them.
If practitioners believe that communication is possible, many of these barriers can be addressed. If practitioners fundamentally do not believe it is possible, it will not happen.
Consent was a major issue in the project, not only because of its usual relevance to research, but also because the whole study was about finding ways of involving people in making decisions and choices about the way things happen, and participation in the project itself was a very immediate example of this.

In the field of research with people with dementia it has, until recently, been the practice of researchers to approach the relative or relatives of the individual in order to obtain consent ‘on behalf of’ the person. The assumption that the person with dementia was unable to take any meaningful part in this process was routine and unquestioned.

A different approach to consent was adopted in this study, which had as its central aim the attempt to provide the best chance for the person with dementia to understand what was being asked of them, to make an initial decision about whether they wished to take part, and to continue to make choices about this.

A novel procedure (referred to as the Consent Procedure) was devised. It comprised three stages. The first stage involved providing relatives with information about the project (in the form of a leaflet), and asking them whether they had any concerns about the idea of staff approaching the person themselves. The second stage was approaching the individual with dementia and explaining, also with the help of a specially designed leaflet, whether they would be interested in participating. The third stage was that of continuing consent whereby staff members continued to remind the person about the project, and check if they were still willing to be involved. The procedure is depicted in Figure 2.
Many issues were raised in the course of using this approach. They are discussed later in this chapter.

The development of this approach to consent constituted a major part of the preparation for fieldwork, and included a considerable amount of consultation with staff and managers about the exact form it should take. In addition to being feasible for staff to use, it had to balance:

- the needs of the person with dementia to be central to the process
- the needs of relatives for information and involvement
- the needs of the service both to protect the interests of the person with dementia and to empower them, and to maintain the confidence of relatives.
my need to comply with project values and meet the requirements of ethical guidelines and so on.

The final procedure was a compromise between all these demands, and while we were conscious that it was far from perfect, it was felt that it did represent a meaningful advance on previous practice which excluded the individual with dementia completely. The intention was to consider the use of the Consent Procedure as part of the process of the research, rather than regarding it merely as a procedural matter.

The provision of written information

The Consent Procedure was supported by various types of written information. Explanatory notes were provided for staff, an information leaflet was written for relatives, and another for the people with dementia. Information leaflets for relatives were customised for particular settings, and those for potential participants were customised both for settings and for the particular members of staff who were intended to work with the individual. All written information was colour-coded to aid the identification of the intended recipient of the material. This strategy may also have had the effect of supporting memory skills, since it would probably be easier for someone to remember or recognise a document that was distinctive in terms of colour and design (copies of all documents are included in the Appendix).

The main considerations in producing the leaflet for relatives were:

- the need to provide enough information about the aims and probable methods of the project without going into unnecessary detail
- the need to make the content of the relative’s leaflet compatible with the one designed for the person with dementia in case the person with dementia had access to both
- the need to describe the project in terms which were likely to be compatible with both the relative’s and the person’s understanding of the condition: this meant avoiding the use of the word ‘dementia’, in case that term had not been used previously. For this reason the term ‘memory problems’ was used. It was recognised that this could be criticised on the grounds of being euphemistic, but it was felt that it was not within the scope of the project to challenge people’s understanding of their situation in ways that could be upsetting.
The main considerations in producing the leaflet for the person with dementia were:

- the need to produce something which balanced the person’s need for accurate information about the project without going into too much detail
- the need to aim for visual clarity and distinctiveness
- the need to produce something which staff could easily use with the people with dementia, elaborating and offering further explanation if necessary.

It proved very difficult to meet these specifications. The provision of written information for people with dementia is a subject which has not been properly tackled in this field, but guidance from related fields such as learning difficulties and working with stroke survivors was used.

In addition to the two information leaflets, there were three forms. One form was intended to be used during Stage One, and completed by the relative. This form asked the relative to confirm that they:

- understood the aims and nature of the project as explained in the leaflet
- understood how to obtain further information if needed
- did not know of any reason why their relative should not be approached regarding the project.

It is important to note that this form was not a consent form, although in the course of discussions about the Consent Procedure with staff it was sometimes referred to as such.

A choice of two other forms was used as part of Stage Two of the Procedure. One was intended to be completed by the person with dementia with help from a member of staff. In order for the connection between the form and the information leaflet to be reinforced it was also yellow in colour. This form restated the main points about the project, and reiterated that participation was a matter of choice. The other form functioned as an alternative to the yellow one. It was intended to be used in situations where the member of staff felt that it would not be meaningful, on account of their cognitive difficulties, to ask the person to complete the yellow form. This one was designed to be completed by two members of staff, asking them to confirm that:
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- they had made reasonable attempts to explain the nature of the project and the implications of participation to the person, but did not feel that the individual was capable of completing the yellow form

- they did not feel that the person with dementia was unwilling to take part or distressed by the prospect

- they would continue to remind the person about the project, and check out that they remained willing to take part on an ongoing basis.

Some of the conversations undertaken for Stage Two of the Consent Procedure were recorded, and these provide a useful sample of the types of issues which arose.

There was no documentation for Stage Three of the consent procedure, but some of the staff used the information leaflet to remind the person with dementia about the study.

Issues raised in use of Consent Procedure
Discussion of these will be organised according to the stage of the Procedure to which they relate, followed by general issues.

Stage One
Some staff expressed concerns about the appropriateness of the practice of approaching relatives prior to raising the subject of participation in the project with the person themselves. They felt that this was disempowering to the individual. This is a valid concern, and was anticipated at the stage of designing the procedure. The decision to do so was made in recognition of the possibility that relatives may have known of a specific reason why approaching the person was inadvisable. Also this practice was adopted in recognition of the importance of services maintaining the confidence of relatives, involving them and seeking their advice when appropriate.

It was recognised at the design stage that the procedure did in effect mean that relatives had power of veto over the participation of an individual in the project, even when the person themself might have been willing to take part. This did seem at odds with the basic values of the study, but was again accepted on pragmatic grounds. This scenario did not in fact arise in the course of the work.

Another situation which did present itself, however, was where the person with dementia did not have a relative who could assist with Stage One of the
procedure. In one case an alternative appropriate person was identified and acted in this role. In two other instances it was felt that the person with dementia was able to decide for him/herself, and that the involvement of another person was not necessary. In these instances it would have seemed inappropriate to have contacted a very distant or uninvolved relative merely for the sake of conforming to protocol. Indeed this very view was expressed by one of the participants.

Only three sets of relatives raised concerns as part of Stage One of the Procedure. One spoke to me directly, and seemed mostly to wish to express his doubt that his relative would be capable of helping with the project. Both other sets of relatives spoke to members of staff. One set was concerned about how much personal material the participant would be encouraged to share, and the other asked more generally about how approaches would be developed.

**Stage Two**

A central issue which was raised in the use of the Procedure was that of asking the staff member to do the direct work in terms of approaching the individual, and talking to them about the possibility of participation. The rationale for this strategy was threefold:

- that, since it was to be the members of staff who were undertaking the fieldwork, it made sense for them to approach the potential participant regarding consent

- that, based on the knowledge of the member of staff about the person with dementia and their style of communicating, it would be easier to determine whether or not the person was willing to take part in the project

- that exploring the issue of consent would be a useful introduction to developing approaches to service user consultation.

Feedback from the staff indicated that they had found aspects of the procedure quite difficult to undertake, particularly attempts to explain about the rationale and nature of the project itself. They described difficulty in providing clear explanations, especially since it would only become clear in the course of undertaking the work exactly what form it would take. Judging whether or not the person with dementia had understood sufficiently well to respond meaningfully was another challenge. Examples of comments from the feedback exercise, in response to the question, ‘What do you see as the main problems of the Consent Procedure, especially Stage Two (talking to client/resident) and Stage
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Three (continuing to remind the person about the project and check if they are still happy to take part)?, included the following:

“In our case in [name of setting] the severity of dementia in our patients makes it very difficult if not impossible to know what understanding they have.”

“The problem I envisaged is that, because of the residents’ illness, their understanding levels are not always the same from day to day.”

Sometimes, on the other hand, staff were struck by how well the individual did seem to grasp the nature of the request being made, and they were confident that understanding had been achieved. Staff from one setting commented on their surprise when one lady demonstrated:

“... her almost immediate understanding of what was wanted from her, and her suggestion that we ask others too!”

Some members of staff felt that although they had the sense that the person was agreeing to help, this may have been based more on the nature of their relationship with them than on understanding the specifics of the request:

“It was difficult sometimes to confirm if the client fully understood or if they were just agreeing.”

“The resident almost immediately forgot the question or thought the right thing to do was to say yes as it pleased us.”

Concerns that the person with dementia only agreed to take part in the project because it was someone who was familiar and on whom they were dependent for care were raised by some staff. It is certainly right for us to consider whether a degree of coercion, however gentle and unintended, was operating. The alternative would have been for me to undertake this aspect of the work, but this would have meant that the very valuable assets in terms of existing rapport and expertise would not have been utilised, and important opportunities for staff to explore the implications of issues of consent would have been lost. Arguably, too, the person with dementia may have incurred more distress by being faced with an unknown person making a request of them.

Another specific observation made in the course of using the Consent Procedure related to terminology. A member of staff in one setting noted:
“The biggest problem was the word ‘project’: trying to explain to participants what we were doing without this word, as they didn’t seem to understand its meaning.”

**Stage Three**

There were particular challenges inherent in carrying out Stage Three of the Consent Procedure, which involved checking out on a continuing basis whether the person with dementia remained willing to participate in the project. The meaningfulness of this stage of the procedure was dependent on the person having achieved a reasonable degree of understanding in the first place, and being able to relate subsequent conversations back to the initial discussion. This would obviously present problems for many individuals.

Although many managed it very well, it nevertheless proved quite difficult for the staff to keep focused on this phase of the Consent Procedure. It was also challenging for me to keep track of how staff were faring in terms of this. One member of staff said:

“\(I\) think the only problem was with myself. Making sure I remembered to start with the Consent Procedure every time I was working with R.”

The fragility of opportunities for communication, and the likely negative effect of launching into renewed discussion of the project at these times, was highlighted by the following:

“I don’t believe it was necessary always to remind J of the purpose of the questions as we could lose spontaneity.”

There was also the fact that given the nature of some of the work which was undertaken, for example observation of non-verbal communication, opportunities for useful work would have been lost if members of staff had had to approach the person and ask for permission to carry out observation. In these situations the only feasible alternatives would be to seek permission after the period of observation, and to try to establish at other times that the person was not averse to continuing to help with the work. This is related to questions about how well staff were able to link work undertaken for the project with that which formed an integral part of the person’s care.

In some settings, staff made particular use of the yellow information leaflet which was designed for the person with dementia as part of carrying out Stage Three of
the Consent Procedure. In one of the group initiatives the practice of getting the leaflet out and allowing time for participants to look at it and talk about it seemed a very effective way both of checking on their continued willingness to help, and also to help them to focus on the purpose of the activity.

In addition to the leaflet itself, staff in this setting requested that I provide a photograph of myself (a small photograph was included in the yellow leaflet, but this was rather indistinct), which could also be used as an aid to helping participants to understand that recordings of their discussions would be passed on to me and the staff would talk to me about their work. This seemed to work very well.

I was very conscious of the demands being placed on staff through the use of the Consent Procedure in the project. It seemed that many of the questions and possibilities the project as a whole was setting out to explore were being called upon at this very early stage, but this was of course unavoidable.

**Advantages of staff undertaking this work**

During discussion of the experience of using the procedure while this stage of the work was the main preoccupation, and through feedback at the end of the collaboration, it became clear that this aspect of the project had stimulated a great deal of interest and discussion, and seemed to have resulted in a heightening of awareness of issues of choice and participation generally.

Comments from managers on this subject (in response to the question, ‘Apart from being necessary for the research, do you think that the experience of trying out the Consent Procedure was useful for staff in any other way?’) included the following:

“It made them think about residents’ rights, advocacy.”

“It confirmed that people with dementia can and should be fully involved in all aspects of their care, and this should be emphasised at every opportunity.”

“I think it highlighted the importance of explaining things, allowing for people to make informed choices.”

“I am a great believer in rights and choices. By using the Consent Procedure it made staff more aware of the importance of enabling residents to make choices.”
“I believe [staff] saw this as a useful introduction to the project – a particular challenge in communication with people with dementia – finding our their views and gaining permission.”

“It was the beginnings of what was to come in the project!”

Although most often encountered in a research context, consideration of the issue of consent certainly should not be restricted to this, and has major implications for care practice. This is only beginning to be recognised as principles of service user involvement gain a higher profile, and there needs to be much more discussion of the implications of this at all levels.

It is hoped that work on approaches to consent undertaken as part of this project can contribute to a wider debate about how this matter should be addressed in both research and care practice.

**Summary**

This chapter discusses how the issue of consent was dealt with in the project.

The research itself had to address issues of communication in the running of the project. Topics of involvement, communication and consent became very real and practical.

There were many challenges in implementing the Consent Procedure designed for the project, but it raised a lot of issues which were useful discussion points, and informed and guided subsequent work.

It was possible to take the lessons of involvement in service delivery into the research and lessons from the research into practice. This is an area which deserves much more attention.
The success of the project depended directly on the contribution of staff in the various settings. And since the aim of the work was to explore the process of service providers undertaking consultation work, their experiences and reflections were of central importance. The usefulness of the main outcome of this phase of the work – the training materials – will be related closely to how applicable they are to situations in ordinary service settings, and this is another reason for paying close attention to the comments of the staff who took part in the study.

Another reason for giving careful consideration to what staff said about the experience of taking part is that through this it is possible to discern certain outcomes of their participation – what effect being involved had on the way they thought, felt and acted in relation to their work. Although I did not set out to measure or evaluate behaviour or attitude change in staff, there are vital clues here as to what the crucial ingredients were.

This material is organised around various themes which seemed the most pertinent both to understanding what happened in this project, and in thinking more generally about how service providers can be encouraged to incorporate consultation work into their pattern of provision.

**Levels of confidence in staff**

As has already been detailed, when first invited to take part in the project, alongside their interest and appreciation of the importance of the work, many staff reported feelings of apprehension about what would be involved. They expressed a lack of confidence about whether they would have the knowledge, skills and time to undertake useful work. Happily, over the duration of the project, for most people these feelings gave way to more positive expectations, but it is important to examine what the crucial factors that allowed this positive change to take place were.

The aim of helping staff to recognise and value their existing expertise was upheld from the start of the collaboration, and was first introduced in the initial workshop. Subsequently it was reinforced through the character of the conversations I had with staff, and in the feedback they were given following work undertaken. It seemed that once they had made this connection, there was a freeing effect which allowed them to go and build on what they had.
Outcomes: what happened for staff

When asked what had helped them to move on from their initial thoughts and feelings about the project (‘If you have changed your views [whether positively or negatively], what do you think has brought this about?’), staff said things such as:

“I am a lot more closely relaxed about the project especially knowing that my client and I can work on something special together.”

“I think mainly being able to relax as I felt slightly uneasy in case I was doing it wrong.”

“Yes, as time has gone by I’ve become more confident about what I’m doing.”

“[The project] has shown us how much we already do unconsciously.”

“It has given me confidence and I feel well able to pass on my experiences to other colleagues.”

Managers also commented on this:

“The project has been a great success in personal development. Staff are more confident, more able to reflect and learn.”

“They have discovered their own talents and the effect they have on others.”

The importance of constructive feedback on performance was also mentioned in this context:

“I feel that the project has enhanced the team as a whole, but, as I’ve said, the positive feedback reassured and reinforces to them that they do have the skills and knowledge.”

These findings indicate that in order to help staff to develop and change their practice we must find ways of affirming the qualities and skills they bring to the work in the first place. Doing this will raise the self-esteem of staff. People are much more likely to invest in improving something they already value and feel is valued by others.

Interest in and awareness of communication issues
Closely related to the issue of confidence is that of interest in the work. In order to care about something we must feel that it merits our interest. We are fortunate in
this respect because most people find the subject of communication not only interesting but actually fascinating. Placing great importance on expressing our own needs and feelings and learning about the feelings and needs of others is deeply woven into our evolutionary make-up. As social animals we need these skills to survive. As regards work with people with dementia this potential for fascination has suffered from the fact that traditionally people with dementia have been seen as being no longer fully human. With their recent reinstatement to the status of persons, we have a great range of possibilities to discover.

The services and staff who took part in the project were clearly already committed to upholding the personhood of those in their care, but their comments demonstrate that an increase in their awareness and interest in the possibilities of enhanced communication was an important part of their experience in the project:

“My views have become more positive, the more I have become involved, and realise the many and varied ways of communicating with people with dementia.”

“I have become more and more interested and involved as the work goes on.”

“Once the project got going I found that the subject became so intriguing that it was hard not to think about it.”

Finding means of harnessing the natural interest of staff in issues of communication is an obvious way to elevate standards of practice. Often this seemed to come about not by asking staff to do things which were very different from the norm, but rather to approach those tasks in a different way – with attention to what the person is trying to tell them about how they feel and what they need from others. Another crucial aspect of this (and this is again reflected in the comments of staff) is that often what is most significant is what happens on a fine-grain level:

“I find myself noticing a lot more of the residents’ non-verbal communication to different things.”

“The project made me think about communication a lot. Whether it be by word, smile or winking of an eye.”

It is impossible to over-estimate the importance of this point. If staff are encouraged to look for and bring about unrealistically marked changes, they will not only become disappointed and discouraged, but will fail to grasp the subtlety, and the
pleasure which can accompany the appreciation of subtlety, in their everyday work. And not least, those people with dementia who desperately need us to slow down and adjust our focus will continue to have their experiences and needs misunderstood or ignored.

We need here to give some consideration to the part interest in communication has to play in caring for people with dementia. An important point is that interest in communication per se should be a stepping stone to interest in persons themselves. Over-attention to the detail of communication could potentially be as depersonalising as the opposite. We need to allow communication to be the vehicle for developing relationships. When it works well, we should be less conscious of the thoughts, feelings and actions which constitute communication, and much more aware of the reality of the other, the experience of encountering them, and possibilities this confers in terms of mutual self-development.

This leads to the final point here which relates to the potential of genuine communication not only to enhance but actually to transform the experience of providing care for people with dementia. Because we cannot have direct knowledge of their experiences and perspectives, we have to be more tentative about the idea of it working in this way for people with dementia, but this is a possibility too. This may appear to be a large claim, but perhaps if we could devote enough of our energy to helping staff to find and use these keys, then work with people with dementia could be a very different sort of experience than it is for many at present.

**Day-to-day practice**

Alongside the positive changes in their views and ways of thinking, many of the staff identified specific changes in what they did from day to day. There were several types of response to the question, ‘Has anything changed in the way you carry out your everyday work as a result of taking part?’, but many of them mentioned the all-important word ‘listen’:

“Watch and listen more carefully.”

“I listen more carefully to what people are saying and the way they say things.”

“We’re much more aware of the non-verbal communication and take more time to really listen to the verbals.”

“I think more about what a confused person is trying to say and listen even if it means stopping what I am doing at the time.”
Communication and consultation

“I listen more and acknowledge the importance of speech and its meaning in conversations. No matter how muddled it may seem, it has a meaning.”

Another practitioner spoke of how her existing commitment to communication had been strengthened:

“I am always trying to discover new ways of communicating with N. I would say the project has made my search for new ways of communicating more intense.”

Non-verbal communication was mentioned specifically by several of the staff:

“Increased awareness of the small but significant aspects of communication.”

“I am more aware of nuances of behaviour and look and listen for signs of communication in all our clients.”

“It has made me more aware of non-verbal communication especially.”

Some of the responses indicated that staff were paying more attention to the ways they themselves communicated:

“It has also made me aware of the way I talk or the words I use.”

“Yes, I now try and converse on a one-to-one basis as sometimes I tend to address people in a group.”

“Yes, the way I speak and use dialect when appropriate.”

“I also try to make sure all the clients understand what I am saying, I did this before but I am more aware of it now.”

“Since seeing the transcripts I think about how I phrase questions, statements, etc, to people with dementia and realise that clarity or lack of it can have a huge impact.”

“I seem to be asking everyone for their views on things more now than I used to.”
When managers were asked whether they had noticed changes in the day-to-day practice of staff, they said:

“Staff seem more interested in getting responses. Has raised awareness for some particular clients. Ideas can be applied to other patients.”

“They might think more about communication and consult more in their day care by discussing issues.”

“Noted that comments in handovers referring to communication in other clients have been given as a response to what was learned in the project. It has generated discussion.”

“If one form of communication doesn’t work they don’t give up, they try other things.”

“Staff seem to realise now that the views and preferences of clients with dementia can be obtained by various means.”

As stated above, the project did not set out directly to change people’s behaviour, and no attempts to quantify or evaluate behavioural change were made. It is well known that self-reports of behaviour change are also notoriously unreliable in social or psychological research. The staff were also under some pressure, both on account of their loyalty to me and also in justification of the effort they had expended, to give positive responses to these questions. However, it is important to notice that these comments are not making dramatic claims. They focus on the type of everyday detail which is the stuff of this work. The fact that managers endorsed their descriptions lends further credibility to their reports.

**Awareness of how services affect people**

An indirect aim of the project was to help staff to think in new ways about the care they provide. After all, finding meaningful ways to involve people with dementia in the design of their own care, and seeking feedback about their experience of that care, entails a capacity to ‘de-centre’, to move away from a purely service provider’s perspective, and try out someone else’s shoes.

Some of the things that staff said indicated that taking part had prompted them to gain new perspective on the relationship between services and individuals:
“Being asked to focus on specific areas of services provided has certainly made me more aware of them and how they affect individuals.”

“The project has caused me to look at the services we provide in a different light and try to be a better listener to any comments residents may make about them.”

In retrospect, it would probably have been very useful to include as part of the project work more specific efforts to help staff gain a better understanding of the experience of being a service user. Ways of doing this could have included them spending time ‘in role’ as a person with dementia, for example, spending time sitting in one place, being assisted with eating or drinking, or being ‘encouraged’ to take part in an activity.

**Quality of relationships with service users**

Care takes place within relationships, however brief or longstanding, and it is surely the quality of the relationship which is the biggest influence both on the experience of providing and receiving that care.

The subject of individual relationships between staff and persons with dementia often came up during discussions with me, and spending time in the settings and meeting many of the participants allowed me to have first-hand experience of these relationships. This was almost always humbling. I was very struck by the qualities of warmth, understanding, affection and mutual enjoyment which characterised them.

Often when staff spoke about the people with whom they were working there shone through very clearly feelings of respect, admiration and real fondness. Indeed it seemed to me that part of the reason for the success of the work as a whole was the fact that I was interested in these people, and the staff very much valued the opportunity to share their feelings about them.

Despite the strength and depth of the existing relationships, many of the staff commented on how taking part in the project changed their relationship with individual people with dementia, and their perception of them as persons. They said things like:

“My relationship with J has become deeper – probably because I listen to her and talk to her more.”
Outcomes: what happened for staff

“It makes you wonder what lies underneath a resident’s life. It gives you an insight into them.”

“You have a better understanding of the client and have built a better relationship with them.”

“It’s made me want to spend more time with G and the other residents in [name of setting].”

One of the managers commented:

“I have become more aware of the staff’s feelings towards the clients. Some have been genuinely moved by reactions they have got from clients.”

My view is that the nature of relationships between staff and service users, their subtleties, complexities, ambivalences and sheer personal significance, is often ignored in care settings generally. In expecting staff everywhere to provide high standards of care, we are increasingly asking them to engage with service users at a personal level. We are recognising that the full acknowledgement of personhood in people with dementia makes equal demands on our own personhood. At the same time, we struggle with notions about ‘professional distance’ and ‘appropriate boundaries’. The result is that frontline staff are left to operate in the zone where these contradictory views collide with each other, and to deal with the consequences for themselves. The result is that many experience stress, even burn-out and health problems.

At some point we need to address these issues. A real commitment to the consultation and involvement of service users may be one of the main ways these matters are brought to a head. For we are now not only asking staff to take a lead in offering, and be a partner in sustaining, caring relationships, but we are also asking them to seek the opinions of others on the quality of those relationships. What could have a more personal dimension than that?

**Understanding dementia as a condition**

We know that many of those who work most closely with individuals with dementia have little knowledge of the nature of the condition. This is an obvious and unacceptable gap. However, merely making information, for example about medical aspects of the condition, available to staff is unlikely to bring about positive change in terms of quality of care. It may even have the effect of lulling practitioners into a false sense of understanding. The reality is that dementia is an immensely complex
condition which affects each person in an individual way. Perhaps the most helpful
stance we can take in relation to it is an attitude of questioning openness, readiness
to be surprised and always to challenge assumptions. Some of the comments made
by staff indicated that this had been their experience:

“It’s made me more aware of the fact that memories don’t just disappear but
are buried quite deep.”

One of the managers said:

“Some have been surprised by the levels of insight and responses from clients
even though profoundly demented and often said very little.”

**Sustainability of efforts**
The basic aim of the project was to explore what was possible in terms of approaches
to consultation. We did not set out to institute practices with a view to maintaining
them, or exploring what would be required for them to be maintained. Nevertheless,
having had such a positive impact, and seeing and hearing evidence that new things
were happening, it was natural to wonder about their chances of lasting.

When staff were asked what they felt about the chances of new practices being
sustained, they generally expressed hopefulness, but when asked to consider what
would be important in helping them to continue (‘What would help you to
maintain the positive changes?’), several themes emerged. On the matter of the
status of communication work within care practice generally one person said:

“Verbal exchanges to be given as high priority as any other nursing care.”

Predictably, there were comments relating to practical arrangements:

“More staff! More time!”

Some of the staff identified training as part of what was needed:

“We need to have regular training sessions to keep all staff focused on good
communication.”

“The new ‘training materials’ pack should be [an] integral part of in-service
training in all dementia care units.”
“Training pack – explanation of methods for obtaining consent, ideas etc.”

Others mentioned the importance of ongoing support from colleagues:

“Reflection on practice and active listening and sharing of information and ideas with colleagues.”

“Staff discussions.”

“Involvement of other staff.”

When managers were asked about their views regarding the chances of keeping up new practices, they recognised the crucial contribution that they themselves must make:

“I think if I keep the issue on their agenda they will be constantly reminded and the work doesn’t get lost in other duties, so I feel that managers are make or break. If I didn’t feel positive about the work I might not allow them the time, no interest, not supportive etc.”

“I plan to use recording in staff training sessions, and to continue to use other processes in different forms to maintain motivation.”

“Hopefully it will continue – it will be very much encouraged.”

**Summary**

This chapter describes various sorts of changes which staff reported as a result of their participation in the project.

Overall the feedback was very positive. Staff reported being more confident, more able to reflect and to learn. They also reported positive changes in terms of awareness, knowledge and actual behaviour as a result of taking part.

It is still difficult to know what life is like for people with dementia and to know how they felt about approaches on communication and involvement. Comments about the levels of insight and responses from service users, being genuinely moved by the quality of relationship between service user and staff member, hint at the quality outcomes for people with dementia. We have to acknowledge, however, that understanding of outcomes for this group of service users is also at a very early stage.
At this point it is necessary to try to bring the many themes which have arisen in the course of the work together. There is no simple or obvious way of organising these reflections, but since this work followed directly from that undertaken by Malcolm Goldsmith, I have decided to let the set of conclusions he arrived at guide the arrangement of this material.

**Communication is possible**
This apparently simple statement sits atop a complex set of issues. When Goldsmith’s book was published in 1996 this message may have seemed more radical than it does today. In the last five years we have seen major strides in thinking, a great deal more material of a positive nature has been published, innovative projects which demonstrate beyond doubt the continued personhood of people with dementia are taking place, and their results are reaching audiences in journals and at conferences. There is much reason to be upbeat about what is happening, and we surely cannot now go back to old ways of thinking; for example the belief that a person with dementia was an ‘uncollected corpse’ as was common 10 years ago, even among those who were well-informed.

Nevertheless, we cannot afford to be complacent. The public reaction to dementia continues to be characterised by horror and fear. When news of medical ‘breakthroughs’ make the headlines, the images portrayed are of people who are lost, passive, being talked over and requiring total care which damages or even destroys family members. The sorts of pictures and stories which are used in fundraising campaigns are frequently bleak, sometimes even ghoulish.

In addition to this wider public perception, there is the constant stream of new people who are coming into direct contact with people with dementia, whether through family connections or through work roles. The message that the experience of dementia is heavily influenced by how others think about and treat the person, and that communication is the key to continued meaning and relationship, needs constantly to be reinforced.

But what more can be said on this subject as a result of the work undertaken for this project? We can certainly be sure that we have accumulated further evidence
of meaningful communication on all sorts of subjects, including people’s experiences of the services they receive. More specifically we have many demonstrations that people with dementia generally, even those in the later stages of the condition, can and do want to express their needs and preferences. In addition to the important new evidence pertaining to people with more severe cognitive and communication difficulties, we now know that it is possible for staff, without special and extensive training and in the context of ordinary service provision, to consult people with dementia about their experiences.

Goldsmith’s original statement about how communication with people with dementia is possible focused mainly on the capacity of those with the condition. The other side of this, of course, is our own capacity to communicate, and the present project touched on some very important issues in this regard. We turn now to another of the main conclusions from the original work.

**Communication is a skilful task**

It is one thing to say that it is possible to communicate, another to say that it is important to do it, and yet another to recognise and allocate the resources actually to do it.

Although I was collaborating with services whose staff were particularly committed to developing practice in this regard as, happily, many now are, we still need to recognise that our inheritance in terms of ways of thinking about work strongly disposes us all to see what we do as a set or series of discrete tasks which have tangible outcomes. In care settings this tendency expresses itself all too often as a preoccupation with the physical care of persons and the environment, and the perception of a member of staff who is sitting with someone listening to them talk as not really working. Of course anyone who has properly tried to engage with persons with dementia at a psychological or emotional level knows that not only is it work, but actually hard work. Nevertheless our understanding of what it is to work is challenged by this scenario. Although it is easy to disparage settings where the ‘communication isn’t real work’ values operate, this way of thinking originates from deep in our cultural value system, and it is something we will have to get to grips with if care practice generally is to move forward. This is one of the many examples of how work with people with dementia profoundly challenges our values, beliefs and habits.

The next issue we have to tackle under this heading is that of confidence. Over the last few years we have become much more used to thinking about the
psychological aspects of dementia, including the idea that one of the important things which happens to people with dementia is that they lose confidence in their own knowledge and skills. This may be as much a factor in functional deterioration as actual damage to the brain.

But it seems that problems with confidence may not be confined to those with the condition. Even if we think it important to devote effort to genuine communication with people with dementia, if we do not believe that we have the qualities or skills required to do it – if we cannot approach the task with an expectation of success – then our intentions will probably fail. As has already been discussed, confidence was a major issue among the staff who took part in the project. As many of the comments gathered during the feedback exercise demonstrate, a large proportion of the staff initially expressed doubt as to whether they were capable of meeting the challenges the project was setting them. Fortunately, as they were supported in trying things out and as they received positive feedback for their efforts, these reservations were rapidly replaced by a new sense of confidence, pleasure and pride in what they were doing. This ushered in a real flourishing of innovative and reflective practice, and generated a sense of excitement and possibility in both the staff and myself.

It could be argued that some of this anxiety arose specifically because of the demands posed by the fact that this was a ‘special’ project, that staff were being asked to expose their practice to scrutiny, and that the same kind of anxiety would not pertain to normal care work. This may be true up to a point, but this pattern should nevertheless alert us to the fact that even when staff do possess the types of qualities and skills required for successful communication and relationship-building, they may well struggle with a lack of confidence. This could arise from a multitude of factors. The reality is that care work generally, and particularly care work with older people with dementia, has an extremely low status in the eyes of society. The great majority of people who hold frontline jobs have little training, hold no qualifications for what they do, and their work is perceived by others as unskilled. They earn pitiful amounts of money, and career structures are practically non-existent. Surely this provides ample justification for staff underrating themselves and what they bring to their jobs?

These are issues which urgently need to be addressed both at a societal and individual level. In order to release the potential of the existing qualities of staff and provide the best opportunities for them to develop these, we have to devote more energy to affirming their efforts, emphasising the importance of their work and encouraging them to appreciate how demanding it is. It is much easier to
Conclusions: bringing it all together

Invest resources in improving something we already value, and people are always motivated to try harder when they feel they are appreciated.

A further facet of the issue of confidence relates to the matter of role the particular approaches to communication and consultation used in the project had. As staff tried out many different ways of establishing conversations or interactions which encouraged people to express preferences, an important idea began to emerge. The reader may recall the concern expressed earlier that we did not fall into the trap of thinking of the things that we were doing as ‘techniques’ which could be isolated and practised with an expectation of a particular outcome. However, we did have to find ways of getting started, and these had to take specific, practical forms, hence the great deal of talk about particular approaches. During the fieldwork phase alongside feeding back how the person with dementia had responded and what had happened, discussions with staff who had tried out initiatives often focused on aspects of the approach and whether it should be repeated, modified or even abandoned.

As this type of work went on, I increasingly had the feeling that what we were actually doing was providing a justification or ‘container’ for the staff to devote time and energy to do something which was somewhat different from their normal routine – to focus on the enterprise of communication with another human being and to try to find out more about the other person’s point of view. In this sense the particular approach used was secondary to what was happening at a more fundamental level between two (or more) persons.

This is not to disparage this type of approach completely, however. It was necessary to finds ways of helping the staff to get started, and doing it in this way set the scene for subsequent learning. If we had been able to continue for longer, it may have been possible to shift the balance away from seeing the approach as primary, and focus more on the essentials of the interaction and the relationship.

We have to achieve a balance between finding and using ways of getting started and therefore having something to do and reflect upon on the one hand, and on the other being able to be flexible and not approach-driven – to modify or even abandon a particular approach when it is becoming less useful or when another avenue presents itself. This certainly demands a particular kind of confidence in staff.
Dementia affects different individuals in different ways
Again this is an idea from Goldsmith’s work (1996) which has, to a large extent, taken hold on the way we think about dementia as a condition, how we regard persons affected, and how we go about maximising possibilities for communication. Of course there is still great variability in the extent to which these values inform care in the world of dementia services, and in the wider world we are unfortunately still struggling with the glib perception that all old people are essentially alike, never mind thinking about the issue of individuality among people with dementia.

For many service providers, having woken up to the reality that consultation and involvement are essential elements of a service, there may initially have been a perception that there exists a single ideal model of consultation, for example the use of a standardised questionnaire which should be completed during formal reviews and the like. We now know that this is not a feasible strategy. Recognition of the individuality of people with dementia, and their experience of the condition and its consequences, must carry into our efforts to consult them about their views of services.

As described earlier in this report, the current work started from the assumption that approaches to consultation should be developed from individual starting points, taking into account the characteristics and preferences of the individual, their strengths and needs regarding communication, and the kinds of relationships they have with staff members. The descriptions of individualised approaches and their outcomes provided in Chapter 4 gave a flavour of what was attempted.

The need to approach consultation in this way makes both demands and confers benefits. It clearly means that it is a very much more complex and subtle business than the routine administration of, for example, a standardised questionnaire. It takes time, personal knowledge, experience and energy to do well. However, as was detailed in Chapter 4, if staff can be supported in the right ways, the process of coming up with individualised approaches can be a catalyst both for helping staff to appreciate and deploy their existing resources, and in developing new ones. It is often the tasks we find demanding that are most engaging to carry out and satisfying to complete.

Although the staff who took part tried many different approaches to communication and consultation, in reviewing them all and trying to discern whether there were common features among those that seemed to work, it was possible to identify one particular characteristic. Putting the person on the spot,
and asking them to respond to direct questions about their experience of service use did not generally elicit rich information or feel satisfying and successful to members of staff. On the other hand, the use of more indirect methods was much more successful. The practice of showing people pictures or other objects or stimuli, engaging with their stories, or observing and responding to their actions as they arose naturally in actual situations, were usually the approaches which yielded new perspectives, and created a sense of excitement and further possibility.

There are several possible reasons for this pattern. It could be that for people with dementia being steered towards a certain subject and asked for specific information about it both runs foul of their cognitive difficulties and generates emotional complications. Features such as word-finding problems or trouble remembering about the subject being targeted would be obvious examples of cognitive hindrances. As regards emotional factors, anxiety could relate either to the possibility of failure when being confronted with a specific question, or the feeling of vulnerability when one is deprived of a sense of control over what is happening. We know that people with dementia are subjected to many experiences of loss of control over numerous aspects of their lives, and the emotional effect of these can be very detrimental. Efforts to consult people about their experiences of receiving support are ultimately intended to ameliorate these, so it would be most unfortunate if those very practices added to the pattern of disempowerment. Other possibilities in terms of emotional factors may be a feeling of offence generated by what could be perceived as an intrusion on privacy, or upset if the aspect of the service being focused on has a particularly painful personal meaning for a given individual. An example of this could be feelings aroused by discussion of the subject of intimate care in the case of a woman for whom such situations trigger memories of childhood abuse.

Another possible explanation for the relative lack of success of direct approaches is that, given the large degree of variability in people’s experiences as regards services, the chances of direct and specific probes linking in sufficiently to the individual’s perspective in order to generate a full exchange are low. There may be circumstances in which such an approach is appropriate and successful, but for most this is likely to be too crude an instrument.

It appears then that providing the types of starting point which enable the person to pursue their own interpretations of material, and have maximum control over what they say or otherwise express, are the most likely to be successful. Ideally the experience of success could derive both from meaningful
Communication and consultation

information being communicated, and the person with dementia feeling that the interaction has respected their individuality and dignity, and boosted their confidence regarding further such encounters. Some of the challenges inherent in this type of approach to consultation will be discussed in the next section.

A further important point about variability between individuals which has relevance in this context is that of the variability in the qualities, skills, concerns and interests of members of staff. In addition to their pre-existing differences, there is another level of variability generated by the experience of coming into close contact with those affected. If dementia itself affects individuals in a great variety of ways, it is only reasonable to suppose that it will affect individual staff members in different ways too. This reality adds complexity to the whole picture, but it also adds a great richness. When the care of people with dementia was seen as purely mechanical, essentially meaningless work, the staff who did it were regarded basically as mere operatives, or tools, in the system. Person-centred approaches to care mean that staff must be recognised and celebrated as individuals too, and in the context of developing communication and consultation this variability in what they have to offer can and should be regarded as a resource. As discussed in the previous chapter, relationships are the starting point for care, and different types of relationships can support different types of approaches to communication and consultation. An example of how this could work in practice is that different people could have different roles in the consultation process. It may be that a service user would find it easier to express negative views to someone with whom they have a more distant relationship or less natural rapport.

The importance of the person’s subjective reality
Goldsmith (1996) talked about the importance of finding ways of learning about and entering into the ‘world’ of the person with dementia if we are to be able to communicate properly with them. This idea was developed substantially by the present work, and again, in common with ideas about confidence and individuality, it is productive to turn the statement around and think about the impact our own subjective realities have on what we think, feel and do, and how we go about communicating with and consulting people with dementia.

However, first we consider the issue of how the person with dementia makes sense of and experiences their own world. Each individual person – with or without dementia – has their own way of creating meaning out of what happens to them and what they do. Elements of this may or may not undergo change in the context of dementia, but it is likely that the sorts of beliefs, values and habits
Conclusions: bringing it all together

which guided the search for meaning earlier in a person’s life will continue to
have a bearing on it once dementia has become part of their life. Again this will
be a highly individual matter. A person who, for example, has derived most
meaning and satisfaction in their life from caring for others is likely to experience
being looked after in a nursing home very differently from someone who has
been used to having others meet their needs in many ways throughout their life.
Someone whose occupational role has been a major part of their identity may
interpret the experience of going to a day centre differently from someone whose
identity was more closely defined by the quality of their relationships with
others. These are factors which will have a profound influence not only on a
person’s care needs generally, but also on how they can be most meaningfully
involved and consulted.

Another facet of the individual’s subjective reality relates to their particular
situation as regards the service in question. For example, are they a new or
longstanding user? Through what sequence of events did they come to be in the
relationship they now have with the service? In what particular ways do they use
it? Services are complex entities made up of many different elements, arranged
differently for individuals according to their particular needs and strengths, the
types of relationships they have with others, and a myriad of other factors. To
this extent we could say that each service user reflects a unique ‘version’ of a
service where some aspects are salient and others not, and those aspects which
are salient form a distinctive constellation of elements. Efforts to find out how
individuals feel about ‘their’ service clearly have to find ways of tapping into this.

Like the other conclusions, Goldsmith’s injunction to consider the subjective
reality of those with dementia can also be turned around so that we can reflect
on the influence our own subjective realities have on how we think and what we
do. One aspect of this is the matter of what we think we are doing in providing a
given service for people with dementia, in current jargon what sorts of outcomes
we are aiming to achieve. Again we all operate within certain ‘frames’ – ways of
looking at and thinking about the things we do – and these frames are based on
assumptions. Examples of the types of assumptions which might operate in the
field of work with people with dementia include the perception that it is good for
people to be in company rather than alone, and that it is more desirable for
people to be busy and active rather than unoccupied. Such beliefs are likely to be
associated with the sense that a certain sort of atmosphere in a service setting is
indicative of success, and attempts to find out about service users’ experiences are
likely to be angled in particular ways. For an individual who values quietness and
solitude, however, and for whom time in a day centre has the potential to be a
welcome break from a noisy and chaotic home environment, this sort of frame is not likely to lead to successful efforts in consultation.

Another example of how different subjective realities could get in the way of meaningful communication and consultation relates at the broadest level to what a service is. As has already been noted, the very term ‘service’ is an example of a jargon word, which may have little or no meaning to someone not initiated into this particular way of thinking. What to us is an ‘outreach service’ based at the local Alzheimer’s branch may very well be, for the person with dementia, a person – Callum, who has red hair and freckles, visits once a week and usually has a couple of good jokes to share. What to us is the ‘lunch club service’ could be, to the person with dementia, a place with the ghastly yellow and orange wallpaper where they usually see the daughter of an old friend who died last year. We need to make sure that our assumptions about what we think we are doing when we provide a service are continually challenged by the individual character, meaning and particularities of the experience for the person on the receiving end.

Another way in which these differing realities could affect efforts to consult relate to the matter of which aspects of a service are seen as being most worthy of comment or feedback. For staff who have invested a great deal of energy in, for example, developing a varied and interesting range of activities in their service, it would be understandable if their efforts to elicit views from service users were angled in this direction. However, no matter how carefully and sensitively this is done, such an approach will miss the mark completely for someone whose individual way of experiencing the service is not significantly affected by the type of activities on offer. While we can appreciate that service providers want feedback about aspects of their service which have been particularly challenging to organise, or ones which are felt to be distinctive, unusual or progressive, this will not always be the most pertinent focus of consultation.

How another person understands and thinks about their own experience is very intimately linked with the way they feel about it – what the emotional dimensions of it are. This is another area in which the subjective reality of the person with dementia and our own can be usefully bridged. Along with broader conceptualisations of dementia as a condition, we have become more accustomed to thinking about its emotional consequences, and how particular feelings – for example, anxiety or anger – may affect the way a person behaves. As is the case with many other things, we have been slower to take on board the fact that staff have feelings too, and they are part of the sum of the caring situation.
Alongside those stimulated by their normal work, many different feelings were generated in staff from taking part in the research project. We saw in earlier chapters how many of the staff felt anxious and rather confused initially, and I hope their experiences of excitement, pleasure and pride also shine through in their feedback. For me, as a researcher, there was also a range of emotions. Together with the many positive ones, there was a considerable amount of frustration and often a feeling of exhaustion with the magnitude and complexity of it all!

When these feelings were to the fore, the most creative way of responding to them seemed to be to try to use them to gain a better understanding of how the person living with dementia may feel in various situations. Thus when something we had planned did not work out or when we did not manage to come up with the right new idea, we could think about what might give rise to similar emotions in the individual with the condition. As discussed earlier, the experience of feeling confused was particularly interesting in this regard. This strategy certainly helped me to process the emotional dimension of the enterprise, and I hope it was also helpful for staff.

But it also prompts us to consider the positive potential of making these sorts of links in the course of normal practice as well. If staff could be encouraged to identify more with the emotional experience of the person with dementia, and to see their own feelings as being more similar to the other person’s than different, then this would surely go a long way to helping them reduce the sense of distance between apparently divergent realities. Some may argue that there are risks inherent in such a practice. Could it not lead to over-identification, a loss of professional boundaries, and ultimately burn-out and stress? These are important issues, but as I have previously argued, working with people with dementia in a genuine way already demands emotional engagement, and there are also real risks incurred by pretending that this is not the case.

The final issue we consider under the heading of subjective reality is that of the need for interpretation as part of the communication process. It sometimes happened that in work undertaken for the project the meaning of what participants said or did was fairly clear, either in itself or in conjunction with features of the context or on account of previous familiarity with the individual. At other times meanings were much less transparent. Examples of such times were when the person seemed to be talking about another situation or another time in their life, or when they told stories which may have been accounts of actual incidents or more fictional in nature, or a combination of both.
The challenges of interpreting what another person is expressing and what underlies it are ones we face whenever we encounter and interact with another person – dementia or no dementia. We use what we already know and pick up on a wide range of current signals and information to arrive at an understanding, which in turn guides how we respond, and how the encounter develops. For the majority of us these skills are so well practised that we take them for granted and fail to appreciate their subtlety and complexity. We also tend to overlook the fact that all our interpretations are just that – theories rather than facts. We use what we know, see and hear to come up with the most plausible possibility of what another person intends, and proceed with that, often assuming the interpretation to be the only ‘right’ one.

However, when we do become aware of a lack of clarity we have at our disposal a range of acceptable ways of addressing points of ambiguity in conversation, for example by saying things such as ‘How do you mean?’ or ‘Are you saying that...?’ Most of the time we get by and meaning is successfully conveyed, but even so it is an approximate business, and from time to time misunderstandings and confusions arise. The acceptance of a certain level of risk is, however, necessary in order for communication between people to have any chance of working. An insistence upon certainty would demand obsessive attention to each detail, each idea, the meaning of each word, and would take endless amounts of time and effort.

Over and above this baseline level of complexity, in the sphere of working with people with dementia there can be special challenges. Cognitive and emotional difficulties may interfere with the person’s ability to express their thoughts and feelings clearly, and our frequently distorted ways of thinking about people with dementia and their problems add to the scope for confusion. At the same time, features of the person’s condition can render our normal ways of attempting to clarify ambiguity less useful. For example, when someone who often has a struggle to achieve verbal fluency does manage to find words to express themselves, it would seem crass to stop them every time they say something which is not clear and ask them to explain further. Such a strategy would quickly put an end to opportunity for communication. This is not to say that it is impossible to find ways of helping the person to clarify their meaning, but they probably do need to be specially adapted.

All this means that, in our dealings with people with dementia, the balance of responsibility in terms of the interpretation of meaning is shifted in our direction. It becomes our role to tolerate more uncertainty and work harder to
entertain possibilities for interpretation than it would otherwise. How exactly this is done will depend on many things, and it is not feasible here to go into detail about methods. But one other important point is the need for us to maintain an enhanced awareness of the ‘provisional’ status of what we come up with when we try to make sense of what an individual with dementia is trying to express, and to bear in mind that we may have got it quite wrong. This is difficult to do because we generally like things in life to be more clear-cut. It is cognitively much more demanding to operate in this rather blurred context. A delicate balance has to be struck between having the confidence to proceed in the knowledge of the possibility of mistakes, and becoming paralysed by the worry that we may be on the wrong track.

**We need to give attention to issues of pacing and timing in communication**

Alongside recognition of variability in ways that dementia affects people’s abilities to communicate, from the material Goldsmith assembled there emerged a more general observation (1996). For many people, the speed at which they can absorb information, think and express themselves declines. If we could only do one thing to help people in this predicament, the most useful thing would be to slow down: to move more slowly, to talk more slowly, to give people more time to think about something and to respond, to give people more time to make choices and decisions. It was this feature of dementia which Kitwood (1997) was highlighting when he identified the instance of malignant social psychology which he called ‘outpacing’.

Another facet of Goldsmith’s conclusion regarding pacing and timing was the recognition of the variability people experience in how able they are to concentrate and do things. People who spend time with those with the condition always observe that some times are better than others: while early morning might be a relatively alert period, by late morning the person may be much less capable. The importance of being able to be with the person at the right time is therefore very great.

Much attention was paid to these matters by staff who took part in the project. A lot of the conversations which focused on coming up with ideas for approaches to communication centred around discussing opportunities when the person would be able to make the most of their remaining capacities. This was very complex, however, as so many factors can vary with the time of the day. These include:

- cognitive factors such as capacity for concentration, and what the person’s
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understanding of the situation and what their expectations of it are

• emotional factors such as mood and emotional climate, how they feel about the encounter, the stability of emotional experience

• social factors including the presence or absence of other people, the person’s feelings about those who are present, the behaviour of other people

• temporal features such as the time of day or night, the influence of what the person was doing immediately before the encounter and what they will do next

• physical/physiological factors such as whether the individual is in pain or discomfort, whether they need to use the toilet, whether they are too hot or too cold.

Dementia aside, we all vary in the extent to which we are able to make the most of opportunities which arise from hour to hour and day to day, and in how well we can perform at things. As these factors shift and combine our inclinations and performance fluctuate. Some factors have a disproportionate effect over others. For example, if we are feeling buoyant and confident in mood we can probably tolerate a great deal more in the way of inconvenience and petty obstruction in other respects, than would be the case if our spirits were low and equanimity strained. Normally we can call on personal resources in an attempt to even out the imbalance, but this in itself consumes energy.

If these types of factors operate for all of us, it seems reasonable to assume that they also do so for people with dementia. It is also likely that people with dementia experience the same types of fluctuating pattern in their capacity to cope with and compensate for negative factors and optimise the positive ones. What may well be different for them, however, is that the pattern of fluctuation may be more volatile, less predictable and more difficult to recover from than it would be for oneself. Given their cognitive difficulties and the fact that they are routinely disempowered in their access to help and information, they are likely to be less able to address and resolve the negative effects of these variations, and they are probably also less able to clarify the nature of the difficulty in their own mind and communicate this to others.

The efforts of the staff who took part in the project were subject to all of these influences. There were many occasions when attempts to initiate an activity or engage the person in conversation about a particular aspect of the service
(perhaps one they had expressed opinions about in the past) failed to develop along the lines hoped for by the member of staff. This was one example of where initiatives which were planned were not always successful. Sometimes it was possible to identify likely reasons for the outcome, at other times it was more difficult. What was probably happening was that the person was unreceptive on account of factors such as those identified above. Our impression was that what seemed to work better were approaches which were either loose enough for the person to respond to in the way that was most feasible for them at the time, or to utilise opportunities as they arose spontaneously.

It may strike the reader that it would be asking for the moon to go about trying to establish what the exact optimum circumstances would be for any one individual, and indeed this is true. There are simply too many factors to manipulate individually, especially within the restrictions inherent in service settings. What may be more feasible, however, would be to make efforts to identify what the major ones that can be reasonably easily controlled are for individual service users. So, it may be, for example, that one person so enjoys having a bubble bath in the evening with a particular type of music playing that this helps her to overcome the effects of anxiety or pain sufficiently to be able to utilise the opportunity for a conversation with a member of staff.

How do issues of pacing and timing affect us as people without dementia? The answer again appears to be that there are many respects in which our own levels of concentration, creativity and receptiveness vary. Having acknowledged that genuine communication work with people with dementia is extremely demanding we cannot expect ourselves constantly to maintain the intensity of focus required to function at optimum levels. This means that we need to find ways of organising care work so that the rhythms in energy experienced by staff are part of the equation.

The environment has an impact on communication
There is now general recognition that people with dementia are especially susceptible to a range of environmental factors which include features of the physical and social environment. In their efforts to contribute to the project, staff went to lengths to try to find or create spaces which enhanced opportunities for effective communication. This was despite there usually being very concrete(!) constraints on what could be achieved.

In this respect we need to recognise that the physical environments in which people with dementia receive care are still often arranged with the
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preoccupations or convenience of staff in mind rather than that of service users. Exciting developments are taking place in the field of ‘dementia-friendly’ design, and innovative work in the area of enhancing surroundings using colour, art and music is also going on (for example Judd et al, 1998). Communication work can tap into and benefit from this.

Again, looking at the other side of this statement we can see that staff are also oppressed by features of the environment. Working in areas which are noisy, hot or inconveniently arranged wastes energy, leaving staff struggling to compensate. They may be more able to do this than those in their care, but the upshot is that it renders them less effective in their role. Again the basic message is that we cannot truly value people with dementia if our practices and standards act to undermine the wellbeing of those who care for them.

The pursuit of meaning

Underlying all that was done for the project was the assumption that if we approach things in the right type of way we will find pattern and meaning. This assumption operated on the level of the expectation that people with dementia have views and are willing to share them, that staff have the basic knowledge and skills to support people in expressing themselves and, that if we proceed to explore in a sensitive and reflective way, there is plenty more meaning and pattern to be found.

Since much of the focus of this report has been on the staff who spend most time with people with dementia, it is appropriate to close this chapter with a consideration of something which may appear abstract, but in fact follows directly on from all the above. It is the crucial importance of staff having a robust sense of meaning in what they are doing. In order to function successfully in anything we do, we all need to have a positive sense of meaning in it. I suggest that this has two main levels. The first level can be seen as a general, overarching one. It plays several interrelated roles. First of all, it enables us to see what we are doing as basically worthwhile, deserving of the effort we are investing in it. This acts as the basic motivating force for continued effort. Without this fundamental sense of meaning, motivation will fail to kindle and effort is likely to cease. If continued effort is enforced in the absence of meaning (for example, by authority or knowledge of dependence), then the effects are likely to be increasingly alienating to the person, posing a severe challenge to their self-esteem and personal integrity.

Having a robust and positive sense of meaning allows one first to develop and
refine more sophisticated levels of understanding and skill, and second to personalise that effort, to make it one's own and for it to become part of one's own value system. Where person-centred work with people with dementia is concerned, this would express itself through a basic interest in the experience and perspective of the other person, a feeling of there being a fundamental similarity between oneself and the other, and willingness to invest energy in the search for explanations for particular incidents and features of interactions and so on. One of the consequences of having a sense of meaning which has this personal dimension is that although the work is done as part of a job, it is not seen purely in these terms, as separate from oneself. Of course, alongside its positive consequences, this kind of personal commitment has certain costs – for example, in the area of the possibility of emotional exhaustion or even burn-out in the context of especially demanding or unsupported working.

The second layer in this sense of meaning operates at a much more immediate level, and is concerned with the thoughts, feelings and actions of the staff member while they actually carry out work with the person with dementia. The substance of this level of meaning is constructed on a second-to-second and minute-to-minute basis as the words and actions (or the lack of words and actions) on the part of the person with dementia are interpreted and accounted for, and the responses (whether cognitive, emotional or behavioural) on the part of the member of staff, are registered and, in turn, interpreted and accounted for. Of course, such processes are difficult to observe and are not always easily available to introspection and verbalisation by the member of staff. It would also be challenging to find out directly from the person with dementia what they were thinking, feeling and doing, and why, during such encounters.

Although we are more accustomed to thinking and talking about it at a much more general and sweeping level, it is in these very immediate ways that ‘care’ actually happens. This is intimately linked to the nature of the experience for the member of staff. It seems that we cannot meaningfully talk about improving the quality of care for the person with dementia without trying to understand both what it feels like for the person providing that care, and what sorts of attitudes and beliefs underpin the thoughts and feelings which are so important in influencing the meaning of the experience.

Communication is essentially a mutual activity, and whenever we set out to learn more about the experience of another person we have the opportunity to learn more about ourselves. I hope that this is what the staff who invested so much of their time and energy in the work found. The following two comments from
them seem to point in this direction:

“It has been a journey of discovery.”

“You learn a lot about yourself, how you communicate with a person with dementia.”

We are still at an early stage of exploring this work, but we certainly have enough in the way of progress to reinforce our sense of meaning in it, the importance of it, and the excitement and benefits which will be part of continuing to develop our skills and knowledge.

**Summary**

This chapter returns to some of Goldsmith’s original conclusions (1996) regarding the place of communication in the care of people with dementia, and expands on these in the light of the recent work.

In addition to issues regarding how people with dementia themselves communicate, many of the conclusions have been turned around in order to examine how they reflect on ourselves as people without dementia.

The final point relates to the need for staff to develop and maintain a strong sense of meaning in their work with people with dementia. It is this which will enable them to operate in the most sensitive, creative and personally rewarding way.
This chapter attempts to summarise the main messages which emerged from the work. These are necessarily couched in fairly general terms, but their application to specific services should be clear. They are not presented in any particular order of importance.

**It is possible to consult people with dementia about their views of services**
This is not a new conclusion, but it has been demonstrated in more diversity in the current work compared with previous research. This diversity consists in the range of:

- types of services involved
- personnel, including both trained and untrained staff
- levels of disability being experienced by the people with dementia
- types of approach to communication and consultation adopted.

**It is possible for staff to undertake service user consultation work**
Critics of the idea of staff consulting their own users argue that it is not feasible to expect people with dementia to express views of services to those who provide them. The current work has demonstrated that this is not the case, although it is fair to say that issues such as how we can assist people to express negative views need much more exploration.
There are many different possible approaches to communication and consultation
One of the main conclusions from Goldsmith’s work was that people with dementia are affected by their condition in many different ways, and that practice in the area of communication must take account of this. The present study has demonstrated that there is a wide range of ways in which people with dementia express their views and needs, and that opportunities for consultation must be similarly diverse.

Approaches to communication and consultation must be developed on an individual basis
Related to the above point is that in order to provide meaningful opportunities, the strengths, needs and preferences of the individual as regards communication must be respected. What works well for one individual will not be effective for another, and what is helpful on one occasion may not be useful on another. These realities demand that staff utilise highly sensitive, creative and flexible approaches.

Giving the person with dementia maximum control over opportunities for communication and consultation seems to be the best strategy
Staff generally found that things went well when they provided opportunities which allowed the person with dementia to interpret a question or prompt in their own way, and retain control over what was said. Rather than confronting them with direct questions about their own thoughts and feelings, asking the person to speculate on what someone else might think or be concerned about appeared to be the most helpful and respectful starting point.

Devising and trying out approaches to communication and consultation require considerable amounts of time and energy
It was demonstrated over and over again that useful work only came about through the commitment of real effort on the part of members of staff. Developing a particular approach, creating an opportunity to try it out, and taking time to reflect on it and document it, were demanding in many ways.
Communication and consultation should not be seen as a special activity which is set apart from other work

The nature of the project work demanded that I support staff in devising and carrying out particular initiatives, and as such many of these did have a ‘special’ status. However, in the course of exploring the reality of undertaking this kind of work in ordinary services it often occurred that although particular pieces of work could not be started or completed, sometimes opportunities presented themselves which had not been planned, but could be utilised with good effect. Staff probably became sensitised to possibilities for adapting activities or using intervals of time for communication and consultation work which they might have missed prior to taking part in the project. Some of the most successful work occurred in this more spontaneous fashion, and this demonstrated that it is necessary for staff to adopt an open mind, and see opportunities for involving and consulting clients as existing in great variety and integrated with rather than separate from other activities and routines.

Organisational features of services do not always support efforts to undertake work of this nature

Despite the fact that all the services which took part in the project were highly progressive and motivated organisations, in all cases it still proved challenging for staff to find the time and devote energy to undertake the work. There are a multiplicity of factors which have to be identified and overcome in order for success to be achieved. Some of these arise from the fact that many organisations are still basically task- and routine-orientated, meaning that the onus falls on individual members of staff to find ways of pursuing work which does not adhere to this model.

Investing effort in developing communication and consultation practice can be highly rewarding for staff

Related to the fact that success in this area demands hard work is the fact that when something goes well or new perspectives are achieved, this is deeply rewarding for staff. Many of the members of staff who took part developed a fascination for the work, and were very excited by the results. This highlights the need for care practice to accord much more respect to the personhood of staff, and the ways in which they make sense of their role, than commonly occurs at present.
**Staff need to be helped to recognise the complexity of the tasks they face and the sophistication of their own skills**

It was again a recurrent observation that staff failed to perceive that they were operating at a highly developed level in their dealings with people with dementia. It was not just that the use of their skills and knowledge had become automatic in the way that normally occurs in any area of skilled performance, but rather a more pervasive tendency to underestimate or minimise the qualities required to be successful in the role. This lack of confidence expressed itself at times in details of the work, such as when staff were hesitant to attribute weight to the type of hunches and intuitions which arose in response to confused speech or non-verbal dimensions of communication. For some members of staff participation in the project seemed to go some way towards offsetting this but, given the small-scale and short-lived nature of the work, such effects were likely to be transient.

This aspect of the project highlighted, however, that in order for developments in practice of this kind to become widespread, and for the true potential of staff to be realised, a greater level of self-esteem and confidence is very necessary. We must find ways of helping staff to address this, including tackling the low-status image of care work in the public mind generally.

**Staff need to be supported in tolerating vagueness and confusion**

The needs of staff for support in tolerating and working within feelings of uncertainty, vagueness and sometimes outright confusion were prominent and virtually universal. These needs expressed themselves in different ways, at different times and in relation to different aspects of the work, but arose so consistently that the sense that this whole topic was somehow very important was unavoidable. Some of these feelings no doubt arose as a result of the fact that staff were involved in a relatively unfamiliar enterprise – research – but some of it seemed more fundamental than this.

Parallels between the experience of people with dementia, the staff and also myself in this respect also suggested themselves throughout. This may mean that for significant developments in the understanding of dementia as a condition, improvements in care practice generally and in approaches to communication specifically to come about, we need to adopt a more open and creative attitude to our own experiences of vagueness and confusion.
There are dangers in adopting pre-planned ‘frames’
Since the whole aim of the project was to explore the process of staff undertaking service user consultation work, and that time and resources were very limited, it was necessary to develop initiatives which had a ‘frame’ of some kind, and seemed reasonably achievable in the circumstances. For example, a frame could be the setting up of an opportunity for a member of staff to talk to an individual about a particular service or an aspect of it, and to approach this encounter with a plan for how to initiate and develop it. In so doing, however, there was the awareness that the frame could constrain the potential of the interaction, and distort the ways in which the meaning of what the person said or did was interpreted.

An example of this would be approaching the encounter with the expectation that because the person was attending a day care service, and the conversation was taking place within that setting, this would be the main topic of discussion. Another example would be the practice of interpreting a person’s words and actions within the assumption that they are talking about their present life as opposed to another period of their life.

Progressing from general to specific approaches is a rational way to approach the task
The general pattern in the development and execution of the fieldwork initiatives was that of starting at a general level of discussion, activity or observation, and then narrowing the field down depending on what was forthcoming from the person with dementia or seemed significant to the member of staff. Such a pattern was consistent with an exploratory research exercise, but also seemed to be the most realistic strategy overall. However, it is a process which is quite challenging to carry out. Finding starting points in general terms, and then managing to develop these beginnings by identifying and taking the next step demands a high level of skill.

Based on my observations this is probably something which is best done as part of the process of reflecting on and documenting efforts, especially in discussion with colleagues. Over and over again it was observed that small group discussions, which were focused on sharing ideas and the details of incidents, and trying to understand the experience and behaviour of the person, were both highly productive in terms of stimulating further insight and ideas, and also apparently enjoyable and meaningful to members of staff.
There is a need to recognise the importance of apparently small details of communication

It is natural to look for clear and obvious benefits in response to devoting effort to developing practice, and current models of care which demand an ‘evidence-based’ approach feed into this. However, in work with people with dementia, especially people who have high levels of disability and long experience of the various forms of deprivation which accompany dementia, there is a need for staff to learn to notice and appreciate very subtle changes and improvements. These are often non-verbal. This is the level staff have to tune into if the development process is to be fully explored. Many of the staff who took part in the project demonstrated a high degree of sensitivity to fine-grain signals and changes anyway, but this seemed to increase in the course of undertaking the work.

Staff need to be open-minded about approaches which seem unsuccessful

Alongside the many initiatives which did yield positive results, there were numerous attempts which did not, or at least not ones which were perceptible to staff and myself. Although we often overlook it, there is great learning potential in such experiences, and where work with people with dementia is concerned it is especially important to remain open-minded about the reasons for lack of success. Just as there may be many reasons underlying a successful approach, there are likely to be multiple factors explaining an unproductive one. Too often failure is attributed to something intrinsic to the individual, for example the nature of their disability or their attitude to an activity. Taking proper account of interpersonal or environmental factors demands effort, but is likely to lead to a more balanced appraisal of the initiative. If there is too narrow a definition of ‘success’ in the mind of the staff member when they undertake an approach, then types of response which do not conform to this preconception will probably not be noticed. For example, a telling non-verbal signal may be overlooked if a member of staff is only looking for a verbal response.

Documentation and reflection are important parts of the process

Throughout the fieldwork phase there was ample demonstration that a considerable proportion of the benefit that staff derived from their efforts came from the time devoted to reflecting on what they had observed or tried out or read, whether this took the form of making notes, filling in forms or talking to colleagues or to myself. Such activity had clear positive effects on both the work that staff did and also on the way they felt about it. This has obvious implications for the way practice needs to develop. Staff need time to process and reflect on their work, for both practical and psychological reasons.
Particular approaches to communication may function as confidence-boosters for staff

As was discussed in Chapter 4, a considerable range of different approaches to communication and consultation were tried in the course of the fieldwork phase, some of which seemed more successful than others. Although we put a great deal of effort into trying to find the right type of approach for individual participants and it is likely that the particular features of the approach were a factor in its success, it is important to consider another perspective on these issues.

This is the possibility that, at least some of the time, the specific ways in which an approach was made were secondary in importance to factors which are more difficult to describe but lie in the areas of the disposition and attitude of the member of staff making the approach. Perhaps ‘props’ such as pictures, objects and activities functioned more as a confidence-booster for the member of staff, who as a result felt more able to invest time and energy in communication and consultation work than they would otherwise.

Despite the vision of person-centred care created by Tom Kitwood (1997), the reality in most services is that care is much more task-focused, both in the way that it is planned and organised, and in the way that it is carried out. Even where the culture of an organisation is undergoing change, there is still a powerful pull towards this model. This means that effort which is primarily aimed at learning about and responding to the person’s psychological and emotional needs is still often seen as being less important than that which adheres to a more traditional model and is directed towards bringing about a tangible outcome. For staff who are trying to find new directions within this sort of culture, it may be that having something concrete such as a picture to look at with the person, or a specific activity to initiate, is crucial, providing the structure which legitimates the focus on the person, and their ways of experiencing their world. However, perhaps once a pattern of spending time with the individual in this way is established, the need for external ‘props’ and activities diminishes, allowing a further level of person-centredness to develop.
**Many people with dementia express needs and preferences in non-verbal ways**
For many people with dementia non-verbal communication becomes an increasingly vital way of expressing feelings and needs, and interacting with others. Moving forward demands that we give more attention to this form of relating, including how we ourselves use non-verbal channels. Staff who explored this area found it fascinating – it deepened their understanding of the person and opened up new possibilities for promoting choice and involvement.

**The issue of consent applies to practice as well as research**
Obtaining the consent of participants is an important issue in any research enterprise, but since the whole project was about the consultation and involvement of people with dementia, it had special significance for the current work. It also has central relevance to care practice, however. Efforts to promote choice and respect preferences, and to seek an individual’s consent in decisions, both large and small, go hand in hand.

**Communication and consultation can be personally very demanding work**
Attempts to engage fully with the person with dementia have the potential to touch on painful personal issues for practitioners. Feelings of vulnerability and exposure are always a possibility in the course of undertaking very direct personal work with another individual. Although by giving work of this type labels such as ‘service user consultation’ – creating a ‘frame’ which can have the effect of rendering it rather innocuous – we cannot afford to underestimate what we are asking people to do when they set out to learn about how another person sees and feels about their life. There is also the knowledge that what the other expresses has the potential to change the way we think and feel about our own experiences. In encounters of this nature there is a quality of immediacy, open-endedness and real risk which places considerable demands on both parties.

Again, devising particular approaches which utilise objects or incorporate activities can be helpful in providing a structure or set of boundaries which in turn engender a sense of safety. Such measures may be necessary to help people to get started, perhaps lessening in importance as relationships develop and mature.

The personal costs of communication work also point to the need for staff to be properly supported in their efforts. Exactly how this works needs to be negotiated on an individual basis, but the potential value of peer and group support, as well as supervisory input, should be recognised.
References


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Hearing the Voice of people with Dementia Project
Consent Procedure Information for Staff

The procedure for finding out whether a person with dementia is willing to take part in the project has 3 stages.

Stage 1 Involving relatives
The first thing to note is that relatives cannot give consent on behalf of the person with dementia. However we do intend to involve relatives in the consent process.

They should be given a copy of the pink information leaflet, and invited to ask questions or express concerns after they have had a chance to look at it.

Kate is happy to talk to relatives on the telephone (in person is not impossible but much more difficult) if required.

If the person’s relatives have no concerns they would be asked to read and sign the pink form. This states that the relative knows about the project, and has no further questions. It also asks the relatives to confirm:

that they do not know any reason why the person with dementia would object to being approached to take part in the project
that they do not know any reason why the person would be harmed by taking part in the project.

If the person’s relatives are concerned about the person with dementia participating in the project, and these cannot be resolved through discussion with the member of staff and their manager, the process would not go any further.

Stage 2 Talking to the person with dementia
This is where the person with dementia is approached by a member of staff to talk about the project.

A copy of the yellow leaflet which is personalised for the member of staff should be used as the basis of a discussion about the project.

The staff member should do their best to explain about the project, and what it involves. It is especially important to emphasise that information will go to the researcher, Kate Allan, and be written up into a report. It is also important to point out that names will not be used.

This may have to be done on more than one occasion.

If, in the opinion of the member of staff, the person with dementia understands what is being requested of them and agrees to participate, they should be asked to complete and sign the yellow consent form. A copy of this should be placed in their file and, in addition to this, the content and outcome of the conversation should be noted in the person’s file.

If, in the opinion of the staff member, the person with dementia understands the project and expresses unwillingness to take part, this should be accepted as a response, and noted as such in the person’s file.

If, in the opinion of the staff member, it is not possible to determine how much the person understands about the project and the request to take part, but they do not appear to be expressing distress and anxiety about the prospect of taking part, two members of staff should complete the blue form. This states that it was not possible to determine the person’s degree of understanding, but that the intention is to proceed to Stage 3. Again this should be noted in the person’s file.

Stage 3 Continuing consent
This applies to all participants.

The idea is that we should continue with efforts to:

explain the purpose of the work to people with dementia throughout the period of the project
remind them regularly that there is a special piece of work going on (reference to the yellow leaflet could be made here)
check that they are still willing to take part.

Members of staff should ask participants after every conversation if it is alright for the recording/notes to be passed on to Kate, who will use them in her report.

Finally
Please remember that trying out this type of consent process is part of the research. Write down any questions, worries or thoughts you have about it and tell Kate!

Work tel: 01786 467740

Thank You
Why this leaflet?
This leaflet is being given to a number of relatives of people who use [name of setting]. Its purpose is to tell you about a project that we hope will soon take place there.

The project is based at the University of Stirling, but a number of places in various parts of the country will also be taking part.

What is the project all about?
The purpose of this project is to explore ways of helping people with memory problems to express their views about the services they receive.

It is now the responsibility of those providing services (of all types) to consult users about their needs. This information can then be used to improve the service. This has begun to happen in other parts of the health and social services, but services for people with memory problems have been slower to respond.

There are various reasons for this:

When people do have memory problems they may not be able to remember the services they use.
People with memory problems sometimes have difficulty communicating their thoughts and feelings.
People with memory problems may not, at times, be aware they are using a service.

Recently, workers and researchers in this area have come to realise that people who have memory problems are often able to communicate effectively. It is just that they often need extra help to do so.

We think that it is very important that people who have difficulties with their memory should be given the opportunity to tell us what they think about the services they use.
How will we go about doing this?
Our aim is to try out different ways of encouraging people with memory problems to share their thoughts and feelings and to see which ones are most useful.

The methods we are proposing to try include the following:

A member of staff speaking to the person on a one-to-one basis. If the person agrees, the conversation would be tape-recorded and listened to again later.

Bringing people together in small groups led by a familiar person, and encouraging discussion about services. Again the conversation would be recorded and listened to again later.

Some people have had skills, such as typing, before they experienced memory difficulties. There is some evidence that these skills may remain even after the ability to write has been lost. We would like to give such a person the opportunity to use this method to tell us about their feelings.

Even if a person does not speak, they find ways to tell us how they are feeling. We would like to explore the links between how someone acts and what they think and feel.

We realise that different ways of communicating will work for different people. We hope that this project will help us to find out how we can give people the right sort of help to tell us what they think and how they feel.

What about consent to take part?
Since the project is all about increasing the involvement of users of the services, we will talk to the person about what is involved, and check that they are willing to spend time sharing their thoughts and feelings. General information about the project will be provided for relatives. The Project Co-ordinator (Kate Allan) is available to speak to anyone who wants to find out more.

Anyone taking part is free to withdraw at any time. This would make no difference to any services or help the person is receiving.

What if my relative becomes upset?
We understand that sometimes a person with memory problems can become distressed or frustrated. We will do our best to ensure that your relative is not put under stress. If they do become upset, we would stop at once and offer reassurance and comfort.

Will I receive information about what is happening?
We appreciate that looking after a person with memory problems is often very demanding. At times, it is helpful to have information about whether the person has had a good day, and what might be on their mind.

If you are interested, please get in touch with staff at [name of setting], and general feedback will be provided.

What will happen to the tape recordings of conversations?
All information will be treated with strict confidentiality. If material from a session would be useful for our final report or to present to other people working in the field, all personal references and/or other identifying information will be removed.

If you want further information about the project, please contact:

Kate Allan
Project Co-ordinator
University of Stirling
Stirling FK9 4LA
Tel: 01786 467740

Thank you very much
Asking people what they want from services
Relatives’ Form

This form asks you some questions about your knowledge of the above project.

It also asks you questions based on your knowledge of your relative who lives in [name of setting].

Your name (block capitals) ......................................

The name of your relative ....................................

Your relationship to the above person ....................

Please answer the questions by ticking one of the boxes.

I have a copy of the pink leaflet giving information about the project. ☐ ☐

I understand that I can ask for more information from staff in [name of setting] or from the researcher, Kate Allan (see pink leaflet for number). ☐ ☐

I feel that I know enough about the project. (If you ticked no, please contact a member of staff in [name of setting] or Kate Allan.) ☐ ☐

Please turn over

I confirm that I know of no reason why my relative would object to being approached to take part in the project. ☐ ☐

I confirm that I know of no reason why my relative would object to actually taking part. ☐ ☐

I confirm that I know of no reason why my relative would be negatively affected by taking part. ☐ ☐

I understand that staff in [name of setting] will speak to my relative about whether he or she wishes to take part in the project. ☐ ☐

I understand that my relative is free to withdraw from the project at any time. He or she does not have to give a reason for this. ☐ ☐

I understand that this decision would not affect any help they receive now or in the future. ☐ ☐

Now please check that you have answered all the questions.

If you have answered ‘yes’ to all the above questions, please sign below

Signature.............................................  Date.....................

Thank you
Now please return this form in the envelope provided.
How can you tell people what you want?

This project is to try to find out about the best ways of helping you to tell people what you need to make life easier.

We are doing some of this work in [name of setting]. It is part of a bigger research project.

We think it is important that we find out what people getting help think about that help.

You may like some things at [name of setting], but not others. You may have some ideas about how to make things better.

We know that sometimes it can be hard to talk about things. You need plenty of time and someone to give you encouragement.

We would like to find ways to help you.
To do this, staff at [name of setting] are working with Kate Allan.

Kate works at Stirling University.

If you would like to take part, [name of worker] who works at [setting] will come and spend some time talking to you about your feelings about going there.

If you agree, [name of worker] will use a machine to tape-record the conversation. This will save [her/him] taking notes.

Afterwards, they will talk to Kate about it.

Next year Kate will write a report to tell other people what she has found out from the work.

This report will include what we have learned at [name of setting]. It will not use anyone’s name.

If you have any other questions, please talk to [name of worker] or another member of staff about them.

Your relative also knows about the project. They have been given a similar leaflet.

Please ask if you or a relative would like to speak to Kate. We will arrange for you to meet her.

Please remember:

It is entirely your decision to take part. If you don’t want to, that is alright. You do not have to give a reason if you do not want to take part.

If you start and decide that you want to stop, you are free to do so.

Whatever you decide, this will not affect the help you get here or anywhere else.

Thank you very much
How can you tell people about what you need?

Consent Form

I have spoken to ...................................................... about the above project.
This conversation took place on ..............................

We have looked at the information leaflet.
I have had the chance to talk about the project and ask questions.
I know enough about the project now.
I understand that it is my decision to take part or not.
I understand that if I do not want to take part I do not have to give a reason.
I understand that if I do not want to take part, this will not affect any help I am getting now or will get in the future.
I understand that if I take part, I can stop at any time.
I understand that if I stop taking part, this will not affect any help I am getting now or will get in the future.

I agree to take part in the project.

Signed.................................................................Date...................
Name (in block letters)...................................................................
Signed (member of staff).....................................Date...................
Name (in block letters)...................................................................
Researcher (Kate Allan).................................Date...................
Hearing the Voice of People with Dementia Project

Staff Form

(Please note: This form is to be completed only if it is felt that the potential participant is unable to understand the explanation of the project sufficiently well to sign the yellow consent form.)

Name of potential participant. .... .......... 

A discussion about the nature and purpose of this project has taken place between (name of staff member) and the above-named person.
This discussion took place on .......... ..... (date)

In the view of the above-named staff member, the person is unable to understand this explanation sufficiently well to give consent.

However the above-named person did not show any signs of anxiety or unwillingness about participating in the project.

The above person’s relative has signed the (pink) form confirming that they know of no reason why the person would object to taking part or would be negatively affected by participating.

Our intention is to proceed on the understanding that further attempts will be made to explain the nature and purpose of the project, and that if any signs of unwillingness, anxiety or distress are observed, the person will be withdrawn from the project.

Signature...........................................................................................................
Name (capitals)...................................................................................................
Designation......................................................................................................
Date.................................................................................................................
Signature...........................................................................................................
Name (capitals)...................................................................................................
Designation......................................................................................................
Date.................................................................................................................
1. **General**
Can you remember how you felt about the prospect of taking part in the project back at the start, for example at the workshop we had?

Do you feel that your views have changed much in the time since? If so, in what ways?

If you have changed your views (whether positively or negatively), what do you think has brought this about?

2. **Consent Procedure (CP)**
What are your views about the CP we used in the project?

What do you see as the main problems of the CP, especially Stage 2 (talking to client/resident) and Stage 3 (continuing to remind the person about the project and check if they are still happy to take part)?

3. **Organisational issues**
How did you find talking about things on the ’phone?

How did you find the face-to-face meetings?

What do you think of the handouts I provided (the leaflets etc)?

What do you think of the written feedback (eg workshop write-up, blue reports, reports of recorded conversations)?

If you managed to do any reading for the project, what did you think about this?

Do you have any other views about aspects of the organisation of the work?
4. Approaches to communication
Please look at the list of approaches you used on the front of this leaflet. Then please write comments on the various approaches used with your client/resident.

What do you think were the best things?

What were the least successful approaches?

In retrospect, are there any other things you would have liked to try?

5. Documentation
What do you think of the idea of keeping notes (in whatever format) of the work?

If you kept notes in your own way, how did you find doing this?

If you filled in the forms I designed, how did you get on with these?

If you made recordings of conversations, what were your feelings about doing this initially?

Has this changed in any way since you have actually tried making recordings? What are your views now?
### 6. Relationship of project to your usual work

How relevant do you feel that the things you have done for the project have been to your usual work?

Has anything changed in the way you carry out your everyday work as a result of taking part?

If you feel that there have been positive changes, do you think you will be able to maintain these after the project work ends?

What would help you to maintain the positive changes?

Do you have any other thoughts you would like to share?

Please use this space to continue your answers from before if necessary.

---

**Finally, please answer the following questions**

Do you have any objections to me quoting the material (anonymously) from the initial workshop in the report?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
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Do you have any objections to me quoting the material (anonymously) from this questionnaire in the report?

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*Thank you very much!*

**Now please return this questionnaire in the envelope provided**
1. **General**
   How do you think staff felt about the prospect of taking part in the project back at the start when they first heard about it?
   Do you think that their views have changed much in the time since? If so, in what ways?
   What do you think were the main factors which changed their views?

2. **Induction workshop**
   How useful do you think the workshop was in helping staff to get started?

3. **Consent Procedure (CP)**
   How useful and effective do you think the CP we used in the project was?
   How do you feel staff got on with using it in general?
   Is there anything you think would have made the CP better or easier to use?
Apart from being necessary for the research, do you think that the experience of trying out the CP was useful for staff in any other way?

4. Organisational issues
How do you think the staff got on with the various ways I kept in touch and provided information or feedback? Please comment on:

Phone calls

Face-to-face meetings

Handouts (eg green leaflets)

Written feedback (eg blue reports, reports of recordings)

Reading material

Do you have any comments/suggestions about the way the project work was organised?

5. Communication approaches
Do you have any comments on how the staff got on with trying the various approaches to communication with people with dementia?
| Do you have any suggestions as to how developing approaches to communication could have been done better? | **6. Staff members’ experience of taking part**  
What do you think were for staff the most useful/enjoyable aspects of taking part in the project? |
<table>
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<tr>
<td>One of the aims of the project was to work collaboratively with staff using their skills and knowledge to develop approaches to communication with the participants. To what extent do you think this has been successful?</td>
<td>Do you think there were any drawbacks for staff or things they didn’t like?</td>
</tr>
</tbody>
</table>
| We hoped that taking part would help staff to feel more confident of their skills and knowledge regarding communication with people with dementia. To what extent do you think this has been successful? | What sorts of things do you think that they found most difficult? Please comment on:  
*Actually carrying out communication work* |
<table>
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<tr>
<th><strong>Documenting their efforts</strong></th>
<th><strong>7. Impact of taking part on care practice</strong></th>
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<tbody>
<tr>
<td></td>
<td>Are you aware of any changes in the way staff relate to the project participant(s) generally (ie not when carrying out project work specifically) which you think may be a result of taking part?</td>
</tr>
<tr>
<td><strong>Taking the next step in trying out the approaches</strong></td>
<td>Do you think taking part in the project has had any effect on the way these staff carry out their work with other people with dementia (who didn’t take part in the project)? If so, please describe.</td>
</tr>
<tr>
<td><strong>Anything else?</strong></td>
<td>Do you think the project has had any effect on the way other staff (who did not take part directly) carry out their work?</td>
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</tbody>
</table>

Do you think there is anything that could have been done within the scope of the project to alleviate these difficulties?
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<tr>
<th>Question</th>
<th>Response</th>
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<tr>
<td>What do you think about the chances of staff being able to maintain</td>
<td></td>
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<tr>
<td>positive changes after the project has finished?</td>
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<tr>
<td>What do you think would help the staff to do this?</td>
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<tr>
<td>What form do you think the training materials need to take to be most</td>
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<td>useful? Please comment on:</td>
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<tr>
<td><em>Aimed at which levels of staff?</em></td>
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<tr>
<td><em>To be used individually or in groups?</em></td>
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<tr>
<td><em>To be used alone or as part of another activity, e.g., supervision?</em></td>
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Please use this space (and another sheet if necessary) to continue your answers or add any other thoughts about the project.

**Finally, please answer the following questions**

Do you have any objections to me quoting the material (anonymously) from the *initial workshop* in the report?

- Yes [ ]  
- No [ ]

Do you have any objections to me quoting the material (anonymously) from *this questionnaire* in the report?

- Yes [ ]  
- No [ ]

*Thank you very much!*  

*Now please return this questionnaire in the envelope provided*