



'Connect with us':

**A resource for care home managers
developing services for people with
dementia**

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INTRODUCTION

In 2003 Dementia North began a project to bring managers of care homes in the North of England together in learning sets at intervals over a period of fifteen months to explore their experiences of providing services for people with dementia and to develop their own management practice. This booklet reflects their experiences, the issues they worked on in the sets and the knowledge they gained and shared together. Its aim is to provide managers with some triggers for thinking, some key areas for exploration and some sources of information as a basis for development. Learning sets use a questioning approach and this booklet highlights the need to keep asking questions when working with people with dementia.

Christine Bryden who was first diagnosed with dementia in 1995 says in her book *Dancing with Dementia*⁽¹⁾:

“Try to enter our distorted reality, because if you make us fit into your reality, it will cause us extra stress. You need to enter into our reality, connect with us by touch, or by look. You need to be authentically present, not far away. You need to realise that we are not far away or lost, but trapped by an inability to communicate and to think clearly, to express this strange mixed-up world being created by our brain damage. Think about this inner reality that we are experiencing, and try to connect with it. Be imaginative, be creative, try to step across the divide between our worlds.”

(Bryden 2005, pp.147–8)⁽¹⁾

Stepping across the divide is a challenge. It demands that managers and staff are open, empathic, self-aware and authentic – real in their relationships with the people they are supporting. It asks that they use all their senses to listen to the voice of people with dementia, and all their imagination and creativity to respond. It asks that people give the best of themselves.

Within the text there are references to resources that the managers who participated in the project identified as useful in developing understanding and good practice. All of these resources, but by no means a comprehensive list of the materials that are now available, are listed and referenced at the end of this booklet, together with details of some organisations and websites that provide useful resources for developing a service.

“No one said it was going to be easy but I now feel passionately about the service I am providing for my clients with dementia and I know we are getting there.”

(a manager)

Managing a care home service for people with dementia demands the same high standards as managing any care home service, but the managers who participated in the project identified some areas that particularly challenged them to think in a different way about how to meet their residents’ needs. These are the areas that are explored in this booklet:

- Person-centred care**
- Assessment**
- Planning Care**
- Supporting relatives and family carers**
- Some key areas of care practice**
- The physical environment**
- Managing and developing your staff**
- Assessing your progress**
- Support for the home**
- Service development**
- Support for you, the manager**
- Useful reading, training resources and organisations**

PERSON-CENTRED CARE

“...enter into our reality, connect with us by touch, or by look.”

(Bryden 2005, p.147)⁽¹⁾

Key points

Managers consistently emphasised six key points:

- A person with dementia is a person first with their own life experience and history, likes and dislikes, hopes and fears, relationships, past and present, their own skills and abilities – a person with unique personhood.⁽²⁾
- People with dementia have as much right as anyone to be respected as an adult and to be treated as such.
- The more you know about each individual the better you will be able to relate to them as an equal in the journey through dementia.
- The aim of providing support and care should be a positive one, building on each individual's strengths and abilities, maximising independence and providing person-centred care.
- The most important thing to give our residents with dementia is our time. They must not be rushed as this can be upsetting and confusing, and our proprietors and the regulators need to recognise this.
- You can draw on your own experience and feelings to identify with the person with dementia's reality.

Follow-up suggestion

Read about the theory and development of person-centred care for people with dementia in *Dementia Reconsidered*⁽²⁾.

Practice Example

Elsie was brought up in the countryside outside Birmingham, the youngest of four children and the only girl. In 1938 she moved to London to train to be a teacher and married Jo two years later just before he was sent overseas. Jo was killed in 1944. They had no children and Elsie did not remarry but went on to develop her career as a teacher, ending up as the headmistress of the primary school near where she was born.

Elsie is in the last stages of dementia. She is now unable to move about independently, has to have all her personal care done for her, is unable to speak and has to be fed by staff. Sometimes she gets agitated and screams, sometimes she whimpers, and a lot of the time she just sleeps. So we know the facts about Elsie but what else should we know that gives her unique personhood?

Elsie was always a member of the local choir. She loves English Choral music and had a huge collection of records. She hates the smell of hyacinths as it reminds her of her mother's death when Elsie was only ten. Her biggest treat all her working life was to go and have a chiropody session at a local centre where they knew that what she liked most of all was the foot massage they included in the session.

Put yourself into Elsie's shoes, imagine what it must be like to have all your personal care done by strangers, to smell a smell that only brings unhappy thoughts, and to be deprived of the sounds and touch that bring comfort? If you can do this and support your staff to do this too then you are already beginning to prepare yourself and your staff to step across the divide and connect with residents with dementia.

ASSESSMENT

“You need to realise that we are not far away or lost...”

(Bryden 2005, p.148)⁽¹⁾

All managers ensure that an assessment is carried out before offering a place to a potential resident, and good practice demands that this assessment process continues after admission and for as long as the person continues to reside in the home. It is essential that the individual is involved in this process and that this is seen as the first step in working alongside them as an equal.

If a visit is possible, make sure the person who did the assessment is there to greet and show the person with dementia round. Take your cue from the visitor – a complete tour of the building and lots of introductions may be confusing. If they are staying for a meal, ensure that you know their likes and dislikes, and any assistance they may need.

The Alzheimer’s Society pack *Building on Strengths*⁽³⁾ provides a dementia specific assessment and care planning process that can be used in its entirety or as a model. All the forms for assessment and care planning are in the pack and can be photocopied and adapted for use. The pack focuses on:

- feelings and emotions
- understanding the individual
- strengths and abilities
- the impact of other people and physical environments
- identification of need expressed through behaviour
- balancing the requirements of legal risk assessment with a person-centred approach.

“It can sometimes be hard for families to share information with us about things they find difficult to talk about – the ‘bad’ bits. The pack has questions that are really helpful in getting the information you need in a non-threatening way.”

(a manager)

“Simple things like knowing that George always had coffee at teatime would have made it much easier for him to settle in.”

(a manager)

What information can other agencies share with you?

Raise expectations about your role. Ask if they have been clear with the person with dementia and their carers that you need as much information as possible to be able to make your assessment.

Family and carers

If you are offering a place, it is useful to tell any carers and family that you expect, support and encourage their presence in the home and that they should bring in familiar objects that have real meaning to the person with dementia. Labelling clothing too is even more important if the person is unable to recognise his or her own things.

“I found that families often bring in the ‘best’ things but these may have little meaning if the person’s short-term memory is going. One of my resident’s most precious possession is an old, much chewed panda which belonged to one of her children. I also ask for photographs that the resident can recognise and we put the names on them initially so that the staff can learn who is who and can talk about them. It is so important that if you wake up in a room which may seem new and strange every morning that you have familiar, cherished things to see right away.”

(a manager)

PLANNING CARE

“Try to enter our distorted reality..”

(Bryden 2005, p.147)⁽¹⁾

Care planning is an ongoing and responsive process that should be enabling for the person with dementia, informative and accessible for staff, and provide a basis for learning and assessment. All the information you gather at the initial assessment, and the things you learn about the resident, contribute to enabling the person to have as much autonomy as possible.

The principles of care planning recommended by the Alzheimer’s Society are based on the philosophy of the *Building on Strengths* pack⁽³⁾. The pack has been designed to help care services to:

- Work towards a common philosophy and common goals.
- Consider how to achieve a balanced partnership between staff, people with dementia and their carers.
- Assess what the person is still able to do.
- Focus on important areas of the person’s life.
- Consider how to address the person’s feelings and needs, provide meaningful activities and enable them to have control over their lives.
- Understand that the behaviour of a person with dementia may express a need rather than be a direct result of the disease process.
- Consider how to create a supportive and enabling environment.
- Plan the support given.
- Standardise record-keeping.
- Make comparisons over time.

“People lose their memory and then we start asking them to tell us about their lives.”

(a manager)

Care plans can also be supplemented by a life history or a life storybook. This can be started before admission and added to as more is learnt. The book can include pictures, photographs, mementos and letters, and can also be used as an aide mémoire for residents to talk about and reminisce about their lives. Sometimes a memory box or cork wall boards can be used and items included that involve senses such as touch and smell as well as sight.

Asking about end of life wishes soon after admission and adding this to the care plans is perhaps more important when a resident has dementia. Sensitively handled it can provide reassurance that as the dementia progresses, the individual’s wishes will still be observed.

Selecting the key worker

Think too about matching residents and key workers. This has the potential for creating a very significant relationship with an impact on how the new resident adjusts to living in your home and for their long-term future.

“ I knew that my staff were really thinking in a person-centred way about the needs of people with dementia when I came back from holiday to find that a new resident’s key worker was the handyman. The resident had always been a “Mr Fixit” and our handyman was able to provide him with safe and satisfying activity during the day”.

(a manager)

SUPPORTING RELATIVES AND FAMILY CARERS

When someone develops dementia it has an impact on carers, family members and friends, and everyone has their own individual response to what is happening. Some carers, families and friends will be very supportive while others, for a variety of reasons, may back away. For a carer who feels they have relinquished their role there may be feelings of loss of purpose, of guilt at not being able to maintain the person in their own home and sometimes jealousy of the relationships that develop between residents and staff. This in turn may give rise to feelings of exclusion or a high degree of criticism of the way in which their relative or friend is now being cared for. It is vital for managers to ensure that staff go on learning about the unique experience of each individual with dementia and also the responses of those around each individual. While the person with dementia is your prime concern providing a warm welcome to carers and recognising their support needs can help to sustain relationships.

- Be available to carers and encourage the development of relationships with staff, particularly key workers, and involvement in the life of the home.
- Be clear that, while their loved one may be living with you, their relationships will be respected and supported.
- Enable relatives to be involved in as much care as the resident and they wish. Although done with the best of intentions, it is not always helpful for staff to do everything for the resident, as carers may feel excluded.
- Within the bounds of confidentiality involve carers in decision making, visits by health professionals and others and in any changes in the way in which care and support is being provided.
- Support intimacy and touch in whatever way this is usual for the resident and those close to them and ensure privacy during visits if your resident wishes this.
- Ask for their support when their relative has to attend appointments and encourage them to take them on visits to familiar places.
- Have information available about dementia in a variety of forms and information about sources of information and support that carers can access.
- Provide space and support for carers to meet with yourself or key workers or to meet together if that is what they wish.

"We know not to go into Lucy's room after lunch when her husband comes in as they have an afternoon snooze together."

(a manager)

Demonstrate your and your staff's person-centred approach at all times and help them to understand that while some residents behaviour may appear strange to them you are all striving to enable and support all the residents to have as meaningful lives as possible.

Follow-up suggestion

The Alzheimer's Society provides useful information and booklets for carers.

SOME KEY AREAS OF CARE PRACTICE

Communication

“You need to realise that we are not far away or lost but trapped by an inability to communicate and to think clearly, to express this strange mixed up world being created by our brain damage.”

(Bryden 2005, p.148)⁽¹⁾

Relationships are based on communication and communication is a very sophisticated tool that we use all the time. When supporting people with dementia, staff need to be encouraged to use many different skills to establish and sustain relationships:

listening – giving real attention to what is being said, to the words and phrases that are being used if there is still verbal ability but also ‘listening’ with other senses when verbal ability is lost

observing – the body language, facial expressions, actions

interpreting – whether the words and the body language match, what the person is trying to convey through actions and noises if they have no language left

accepting – apparently inappropriate words or phrases

understanding – the sense and underlying feelings of what is being expressed both verbally and non-verbally

facilitating – maintaining eye contact, being on the same level, getting rid of distractions, not hurrying or interrupting, ensuring the person has any aids they need such as hearing aids, glasses, false teeth, and pictorial representations

accommodating – difficulties that people with dementia may have such as dysphasia or short-term memory loss

learning – everything about the person to aid understanding

empathic responding – reflecting back attention by body language and tone of voice, using words that have meaning for the resident, using their name, giving information or asking questions in accessible pieces, using appropriate touch.

Work with your staff to help them identify the skills they are using. Model skilful communication in your relationships with residents and support staff through training, observation, practice and acknowledgement to enhance existing skills and to develop new ones.

Understanding and responding to behaviour that challenges us

“Think about this inner reality that we are experiencing and try to connect with it.”

(Bryden 2005, p.148)⁽¹⁾

Behaviour is about communication and while some of it is verbal much of it is expressed in other ways. For example:

- George liked coffee at teatime. He tried for days to tell people what he wanted and at last he started getting angry with the frustration of not being able to make himself understood and shouted at the staff serving tea.
- Elsie hated the smell of hyacinths and it pervaded her room. She had no means of telling anyone and she cried.
- Dolly was frightened when two strangers took her into a small room, shut the door and started to undress her. She lashed out at them.
- Mary had a very painful hip and it hurt when she sat down for any length of time. She walked about a lot and became very upset whenever the staff tried to get her to sit down and join in activities.

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- John missed his dog that he had had to leave behind when he came into the home and sat quietly in a corner refusing to talk or join in any activity.
- Sally would not take her medication at bedtime. She was only offered water to drink and she was used to having a cup of cocoa with it.
- Peter took his clothes off in the lounge. He had never had central heating and found the home much too warm.

Each of us is a unique individual and how we respond and react to situations and to other people reflects that uniqueness. This is influenced by such things as our personality, our upbringing and life experience, our culture or religious beliefs, the people in our lives, past and present, and how we are feeling at the time both physically and emotionally. This is the same for people with dementia and it is important to recognise this and not attribute behaviour that challenges us as merely a symptom of the dementia.

It is also important to respect the individual's right to the feelings they are expressing. For instance we all feel angry at times. Our role is to try to understand what has brought on that feeling. Is it something a member of staff has done with no ill intent but which has caused the anger? Is it frustration at not being able to do something, such as to be understood, to open a door, to find the toilet, to have sugar in a cup of tea, to be in pain and to have no one helping with this.

"What is it that upsets Elsie so much at the moment? Are we doing anything different? Is there anything new in her room? Who was in the room when she got upset? Maybe the new handyman reminds her of her husband. Maybe she doesn't like the smell of hyacinths."

(a manager)

Understanding the behaviour involves the use of creativity and imagination, empathy, the sharing of knowledge and ideas between staff, carers, and families and friends and sometimes trial and error before you get it right. Keep on asking the question, "What is s/he trying to tell me?"

Follow-up suggestion

See Graham Stokes book, *Challenging Behaviour in Dementia. A Person Centred Approach*⁽⁴⁾ and Chris Bonner's, *Reducing Stress-related Behaviours in People with Dementia*⁽⁵⁾. Both are very readable.

"I think much of the understanding of the behaviour is about knowing the person. Obtaining a good life history which leaves "no stone unturned" is a good start. To know a person you have to understand what it is that makes that person unique."

(a manager)

Activity

Activity is not about what we do with people but how we engage with people in a therapeutic way."

(a manager)

As individuals we do not consciously think of our lives as being involved in 'activity', but that is what we are doing from the moment we wake up in the morning. It is no different for people with dementia. How we support their activity can maximise independent actions where these are retained, and help to maintain skills and abilities as well as potentially developing new ones.

A model of individualised engagement should underpin the approach and managers need to:

- Develop a culture that recognises that activity is the responsibility of all and not just the activity co-ordinator.
- Ensure that any activity co-ordinator is trained in supporting people with dementia so that s/he can be developing activities appropriate for varying levels of dementia and supporting all staff to be involved.
- Support staff to build on information gathered at assessment to develop a life history/life-story book that helps in getting to know the whole person and thus be able to support their interests.
- Ensure that an activity assessment is completed for each individual. For example The Pool Activity Level Instrument⁽⁶⁾ provides guidance on developing an Individual Action Plan that is based on the appropriate level of activity – planned, exploratory, sensory or reflex – and that supports the engagement of people with dementia in meaningful occupation, which meets their need be it brief or long.
- Educate staff about how to support people to engage in activities of everyday living, for example getting up, washing and dressing with the minimum support to achieve this, laying or clearing tables, taking round newspapers, helping the handyman or the gardener. Remember to ensure residents have choices. As one resident said, “I’ve washed all the dishes I ever want to wash in my life.”
- Ensure creativity about supporting individual interests. Can Peggy continue to knit with modified needles? Can John’s dog come in to visit him? Can he visit the dog or has he got photographs that can help staff to talk with him about his dog?
- Get to know the area around the home. What places are accessible for your residents? Will the local hairdresser or pub provide a welcome? Who could come in and provide friendship or activity?

Follow-up suggestion

Be creative, be imaginative and be sensitive to the needs of each individual.

Contact the National Association for Providers of Activities for Older People (NAPA) and the Alzheimer’s Society for further information and support.

Is it wandering or purposeful walking?

The term ‘wandering’ is often used in a negative way to describe the walking about that occupies some people with dementia. Understandably it can cause upset to others if the person comes into their room often or repeatedly gets up and down from a chair. But why is the person occupying her/himself in this way? Managers need to work with staff to ask questions about what is happening, for example:

- Is Mary bored? Have you ever gone for a walk because you feel there is nothing else to do?
- Is she looking for her room, the toilet, a lost handbag or book or perhaps a person who she feels should be there?
- Is she in pain?
- Is she frightened or bewildered by activity around them, by noise or movement or by the – to her – unfamiliar surroundings?
- Are there particular triggers, patterns or times of day?

It is vital to minimise any reduction in the freedom of residents and to carry out a realistic risk assessment that balances safety with their right to be as free and in charge of their actions as possible. Managers also need to ensure the rights of all the residents are recognised and addressed and balance the needs of all with the needs of individuals.

Follow-up suggestion

See the chapter on ‘Restlessness and Wandering’ in *The Care Assistant’s Guide to Working with People with Dementia*⁽⁷⁾. Also, the website for the Wandering Network (see section on useful organisations below) has some helpful assessment tools.

The twenty-four hour day

For some people with dementia, a sense of time may be lost. They may appear more active and alert in the evening, usually known as 'sundowning'. There may be a reversal of day and night with the person sleeping or napping a lot during the day and being very active at night. Again, ensure staff start by asking questions, for example:

- Is Joan awake a lot at night because she sleeps through boredom during the day?
- Is Agnes very active in the evening as this was when the children came home from school?
- Did John always work the night shift and is more accustomed to sleeping during the day?
- Is Molly frightened on her own in a strange single bed in a strange room and does she go looking for her dead husband and their familiar bedroom?

Learning about the individual's life story, providing activity and stimulation during the day may be helpful but night staff also need to be aware that this night wakefulness may be part of someone's established pattern or may be reflecting the confusion and disorientation that dementia can bring. The night may also be the time when someone with dementia has an appetite for food, the time when they are most able to communicate and also the time of greatest anxiety. It is vital that night staff are selected, trained and supported to meet these needs and also to work with the day staff to ensure that each resident gets the care they need over the twenty-four hour period.

Supporting continence

Loss of continence can be put down to dementia but with correct support this can often be lessened or prevented. It can be linked to the environment, to confusion that inhibits identification, to established habits and patterns. Managers need to develop an approach that supports continence. For example:

- Are the toilet areas easily identifiable and accessible with well lit pictorial and written signs at a level that they can be seen?
- Are the toilets themselves distinguishable from the surroundings with contrasting seat colours?
- Are staff alert to signals that a resident wishes to use the toilet and to their habits and routines?
- Are people given sufficient time, privacy and dignity when being supported, and opportunities for rituals such as hand washing?
- Do you have a range of aids and access to professional advice to support people to remain as continent as possible?

Follow-up suggestion

Graham Stokes' book⁽⁴⁾ provides real insight into understanding reasons for incontinence and how it can be addressed.

Supporting adequate nutrition

“I asked my staff to describe their favourite food experience and one said sitting in her pyjamas, watching TV, and eating a big bar of chocolate. Why then do we sometimes react negatively when we find a resident with dementia doing exactly the same thing?”

(a manager)

For people with dementia appetite may fluctuate and patterns of eating may change. Some people may lose their appetite, some may have no memory of having eaten recently, and others may need food sweetened to make it acceptable. Manual skills may also decline and some people with dementia may find it hard to sit for long enough to eat a meal. When looking at nutrition it is important not only to look at the nutritional intake for a balance diet but also other factors that can support it, for example:

- Can you provide a meal at any time of the day or night?
- Is the food attractively presented to encourage eating?
- Are you supporting independence through providing finger foods or food on the go?
- Is the dining room well lit, quiet and relaxing, with appropriate furniture, crockery and cutlery that aid enjoyment of eating in a social space?
- How is the person’s oral hygiene? Is this affecting their appetite?
- Have you got pictorial menus to aid choice?
- Are you carrying out a risk assessment in relation to nutrition using a researched and validated assessment tool?

Follow-up suggestion

See the Alzheimer’s Society *Food for Thought* programme for ideas and tips, the video *Oh Good Lunch is Coming* from Stirling DSDC, and the VOICES guide⁽⁸⁾.

Pain and pain management

It is sometimes assumed that older people and people with dementia do not experience pain in the same way as others. Within care homes there is a need to raise the awareness of staff to the occurrence of pain in residents and to develop the ability to manage it effectively. Pain can be the reason behind some behaviours and needs always to be excluded when trying to understand what residents are trying to express through their behaviour. This expression can be active such as refusing food as a result of oral pain to quiet rocking to ease joint pain or passive when the resident may become quiet and withdrawn.

Follow-up suggestion

See *Practice Guide for Pain Management in People with Dementia in Institutional Care* and *Facilitator’s Book for Pain Management in People with Dementia in Institutional Care*^(9,10).

Spirituality

For some people spirituality may be related to religion and, if their past history reveals links with particular religions, managers need to support the ongoing expression of beliefs and rituals if that is what individuals want. Even when residents no longer retain the ability to participate, the familiarity of learned rituals, music and prayers can have meaning and give great comfort. Encourage contact with religious leaders and involve them as active participants in the home or ward. If space allows, can you set up a room as a quiet space that can be used by residents of all faiths, and none, for reflection and/or worship?

For other people spirituality may have nothing to do with religion and can be expressed in other ways such as music, painting, gardening or observing nature. Learning about each resident as an individual is vital in supporting their right to express and experience their spirituality in ways that are familiar and that touch feelings that they may no longer be able to express in a tangible way.

Follow-up suggestion

Contact local faith organisations, the Alzheimer's Society and the websites for the Leveson Centre and for the National Institute for Mental Health in England (NIMHE), which has a 'Spirituality in Mental Health' programme.

Supporting diversity

Some homes may be situated in areas where there are a high proportion of people from minority ethnic communities and from different cultures; others may only have one or two residents. Using the principles of person-centred care it is important not to make assumptions about individuals but to work to learn as much as possible about that person's life and how they express their ethnic and cultural background, values, beliefs and practices. Sometimes behaviour is attributed to the dementia that may be a response to care provided in a culturally inappropriate and unacceptable way.

We know that for some people with learning difficulties such as Down's Syndrome there is an increased risk of developing dementia and you may be asked to provide a home for someone with a potential double disability. Again do not make assumptions and conduct your assessment process as you would for any potential resident. The majority of disabled people live their lives as part of the community and arguably most should be able to live within a dementia care home unless there are additional particular needs that you are unable to meet.

While society may have become more open about sexuality, gay men and lesbians still face prejudice and discrimination and this can have an impact on the support homosexual people and their carers experience when living with dementia. This prejudice may also arise within the home, from other residents or staff, and managers need to ensure that this is addressed.

Follow-up suggestion

Contact your local community organisations, the Alzheimer's Society and the website for NIMHE, which has a Black and Minority Ethnic Mental Health Programme. Other useful website contacts are the Downs Syndrome Association and the British Institute of Learning Disabilities. Access support for your residents through local Gay and Lesbian organisations and the through Alzheimer's Society Gay and Lesbian Network (see the Society's website).

Advocacy

“...it is not my job to decide what is best for that person, it is to stand by that person, and to ensure that we get what we can that will carry them on the way they want to carry on’.”
(an advocate)¹

(Cantley et al. 2005, p.6)⁽¹¹⁾

People with dementia sometimes have difficulty getting the service they want or there may be a conflict or difference of opinion between a person with dementia and their carer. There could also be different views about the care between agencies or there may be issues relating to elements of risk that the person wishes to live with in the face of opposition from carers and the home. It is challenging to managers to be faced with these issues but respect for the personhood of each individual can be reflected by willingness to ask for advocacy support for residents.

Follow-up suggestion

In some areas there are specialist dementia advocacy services and your local Alzheimer's Society or Age Concern should be able to provide contact details for these or local mental health advocacy services. Also see the '*Hear What I Say*' guide⁽¹¹⁾.

Mental Capacity Act 2005

The new Act will have implications for providing services for people with dementia and managers will need to familiarise themselves with its contents. Key points include that:

“...every adult has the right to make his or her own decisions and must be assumed to have capacity unless it is proved otherwise...”

“...no one can be labelled incapable as a result of a particular medical condition or diagnosis...”⁽¹²⁾

The Act also provides for Independent Mental Capacity Advocates (IMCA) who can make representations about the person's wishes, feelings, beliefs and values.

Follow-up suggestion

See The Department of Constitutional Affairs website for full information about the Act and its implications.

Managing outpatient appointments and hospital admissions

Most acute hospital staff do not have any training in supporting people with dementia and these places are often busy and, for the person with dementia, can be very confusing and distressing. As a manager you can help to reduce the distress that may result from outpatient appointments, for example, by:

- Making it clear to relatives that they will be expected to continue providing support for hospital appointments. If this is not possible, ensure an escort of a familiar and experienced member of staff.
- Trying to organise transport to minimise waiting time before appointments and for coming home. This may be difficult if reliant on hospital transport, although explaining the situation may help. Getting the family, if there is one, to provide transport can be more reliable.
- Speaking to the senior nurse prior to the appointment and clarifying the particular needs of the person attending. Make sure that s/he will be on duty or ask that the information is passed on to whoever is in charge. You could check on the day that this has been done.
- Asking if any tests or investigations can be carried out in the home by a familiar health care professional.

And for hospital admissions by:

- Pre-empting any problems by liaising with ward managers to agree the information they need that will be helpful in reducing the resident's confusion and distress.
- Contacting the named nurse and working with her/him to anticipate any problems that may arise and to provide support during the admission.
- Clarifying that you will need to reassess the person prior to discharge and being clear about what information you will need to make this assessment.
- Asking to be involved in the discharge planning discussions. You can ask for the resident and carer's agreement to this on admission.
- Getting involved in developing protocols for admission and discharge that serve both the ward needs and those of the person with dementia.

In all instances be prepared to be an advocate for your resident, using your knowledge of them to ensure that any attendance or admission causes them as little distress as possible.

THE PHYSICAL ENVIRONMENT

The physical environment can have an enormous impact on how the strengths and skills of all elderly people are supported or denied and homes will have been adapted to take account of this. There are additional changes that will support people with dementia and help to maximise independence and minimise confusion. These include:

- Using plain not patterned carpets to prevent visual disturbance.
- Having toilet seats that are a different colour to the rest of the room to help with identification.
- Using changes in colour in different areas to help with orientation.
- Using pictorial signs as well as written signs and ensuring these are at the right height to help with identifying different rooms and areas.
- Providing freedom to walk about in areas that are interesting and that do not all end in dead ends, such as corridors that have pictures and sitting areas, or a route into a garden that perhaps leads round to another entrance or exit.

Follow-up suggestion

See *Put Yourself in My Place*⁽¹³⁾ for ideas about designing and managing care homes that maximise the independence of people with dementia.

MANAGING AND DEVELOPING YOUR STAFF

“You need to be authentically present, not far away.”

(Bryden 2005, pp. 147–8)⁽¹⁾

Supporting people with dementia requires staff who are empathic, intuitive and committed to this area of work. While recruiting staff for any home may be hard, getting the right staff for dementia care and retaining them can be even more difficult and needs careful preparation and planning.

Recruitment

- Be clear in your job descriptions and person specifications, and plan your interviews to draw out the qualities you need.
- Arrange for a potential member of staff to spend time in the home meeting residents and staff; gauging their response with people with dementia can be part of the process of selection.
- Ask how they would approach a situation using real examples you have experienced.
- Involve your most aware staff in the interview process.
- Remember sometimes that someone with no experience but who demonstrates empathy and warmth can be a real find.

“I knew we should give her a chance. She went right up to George when he called out and sat with him listening to his stories about the war with real attention, laughing with him and helping him with his coffee in a really respectful way.”

(a manager)

Retention

- Be person-centred in the support of your staff.
- Recognise and praise good practice immediately.
- Recognise the complex skills they will be using and the emotional impact they will experience.
- Ensure good systems are in place for supervision where staff can be supported to bring real problems and have them addressed.
- Have a good written sickness and absence policy, perhaps with a reward structure built in, that you follow consistently.
- Consult with staff at all levels regularly about all aspects of care and the home, and recognise and draw on their ideas and involve them in decision making where possible.
- Ensure your senior staff are providing the same person-centred model of care for residents and staff over the twenty-four hour period and monitor this.
- Recognise the special overnight care needs for people with dementia and ensure night staff are provided with the skills and support to meet these.

“We recognised that things were very different at night. The needs of our clients were different and the staff did not have the interaction with all the people who came in during the day. We recognised this difference and identified the particular skills we were looking for in night staff, recruited staff with these particular skills, provided them with specific training for working at night with people with dementia and also employed a night manager to cover the homes so that the staff had as much support as the day staff.”

(a manager)

Developing your staff

As the manager developing and sustaining a person-centred approach, staff development is a key responsibility for you and your senior staff.

- ‘Walk the walk’ with your staff. Be ‘on the floor’ for part of each day modelling a person-centred approach.
- Encourage the use of imagination and creativity in your staff.
- Make use of handovers to encourage sharing of knowledge and raise topics for discussion.
- Be opportunistic so that every situation can be a learning experience.
- Organise home-based, on-going training for staff.
- Use training packs provided by organisations such as the Alzheimer’s Society, and videos to trigger discussions.
- Access distance learning approaches through local colleges where the learning is focussed on personal experience and experience of working with residents.
- Develop your own training that is tailored to the needs of your residents. There are ‘training the trainers’ courses available.
- Invite in a trainer from the Alzheimer’s Society and share the costs with a neighbouring home. This also provides opportunities for learning from each other.
- Following any training, ask staff to each identify at least one change in practice, however small, and monitor this through observation and supervision. Lots of small changes can have a real effect on the service for your residents.

“I’ve just found out from Elsie’s friend that she loves choral singing. What can we do to bring this to her?”

(a manager)

This week we are using the question, ‘How would you feel if a stranger helped you to go to the toilet?’

(a manager)

The Positive Dementia Care course is excellent and really changed my practice.

(a manager)

Follow-up suggestion

See ideas for sources of training materials at the end of this booklet.

ASSESSING YOUR PROGRESS

All homes will have processes in place for audit and for ensuring quality assurance but when providing dementia care there can be additional ways of gathering information about how you are doing. These include:

- **Dementia Care Mapping.** This is a specific tool for assessing dementia care developed by the Bradford Dementia Group (see their website) which also provides training in using the tool.
- **Support and Supervision.** Without breaching the confidentiality of individual staff members, what are you learning from the support and supervision process about the staff's response to providing dementia care?
- **Observation and Engagement.** What do you notice as you move about the home and engage with residents and staff? While all managers will be doing this as part of their daily routine it is even more vital where residents themselves may not be able to fully communicate their needs.
- **Complaints.** What issues are residents and their carers bringing to you in relation to dementia care? Do you look on them defensively or as a means to address difficulties, to learn and move forward?
- **Visiting other homes and dementia services.** A lot can be learnt about your own service by seeing how others are doing things.
- **Outside agencies.** What do staff from other agencies say about your service? What expertise or insights can they offer you in dementia care? Do you encourage visits for people with no relatives from, for example, the local Alzheimer's Society? Are you open to really listening to what they have to say about their experience in your home?

SUPPORT FOR THE HOME

Community support

Other agencies may be able to offer visiting for residents without relatives, opportunities for residents to take part in activities, and contacts who may offer support.

- Identify agencies that share a common approach such as the local Alzheimer's Society branch or Age Concern.
- Contact NAPA for useful ideas about involving care home staff and their residents in the local community.

Crisis support

Managers and staff in care homes may sometimes feel unsupported by outside agencies particularly when there is a crisis and all the skills of the staff have been exhausted in addressing the situation. Identifying sources of help and support from the outset, particularly during periods when regular support is not available, such as overnight or at weekends, can provide reassurance and access to experts. For example, talk to the social work mental health team, the Mental Health Trust, the local community psychiatric staff or specialist dementia services in your area. What is available? How do you contact them? What support can they offer? Also, be prepared to attend inter-agency meetings to highlight your needs as well as contributing to service planning to meet the needs of the community you serve.

SERVICE DEVELOPMENT

In developing your service it is a good idea to start small with a pilot project. Key steps include:

- Identifying the changes you want to try and the reasons why.
- Finding supporting evidence and people who will back you. This could be a senior member of staff, some residents and carers, your Inspector, your local Alzheimer's Society branch or your proprietor.
- Trying a small pilot with 2 or 3 residents, and/or 2 or 3 care staff.
- Documenting what happened.
- Identifying any improvements and feedback from people who took part. This could include comments from residents and carers, a simple questionnaire used before and after the pilot, observations you have made.
- Outlining the potential benefits for the residents, the staff and the home.
- Feeding back to the people involved and who have supported you.
- Writing it up and presenting it to your proprietor or management team.

SUPPORT FOR YOU – THE MANAGER

Managing a service for people with dementia, supporting their carers and providing support and supervision for staff, as well as ensuring that the service is maintaining all the prescribed standards and regulations, is a very challenging task.

Accessing support and supervision and time for development is indicative of strong management, highlighting someone who wishes to manage effectively and to continue to grow and develop her/himself and their service. It is hoped that the support and supervision needs of managers in the care home sector will be written in to the standards as a requirement.

Follow-up suggestions

- Request that you receive support and supervision from someone who is a trained supervisor and that this is written into your contract.
- Set up a peer support group, or pair support with another manager, where you can learn from each other and exchange experience, knowledge and skills.
- Identify allies among other agency workers and draw on their skills and knowledge. Ask about access to their training and development programmes.
- Be clear with your management team or proprietor that you need agreed time to go on developing your knowledge about care for people with dementia and that this will enhance the service you provide.

Above all be person-centred with yourself, for example:

- Keep a work diary and regularly review how you are using your time.
- Develop trust so that you can delegate to your senior staff.
- Ensure you take your holiday entitlement and days off.
- Try not to take work home.
- Identify things that help you relax and switch off.
- Be kind to yourself.

USEFUL READING, TRAINING RESOURCES AND ORGANISATIONS

Useful reading

This basic list of material cited in the text can serve as a starter for managers who are beginning to develop dementia care and managers who need to develop their knowledge and a resource base.

- (1) Bryden, C. (2005) *Dancing with Dementia: My Story of Living Positively with Dementia*. London: Jessica Kingsley.
- (2) Kitwood, T. (1997) *Dementia Reconsidered. The Person Comes First*. Buckingham: Open University Press.
- (3) Alzheimer's Society in collaboration with Dementia Care Matters (2003) *Building on strengths: providing support, care planning and risk assessment for people with dementia*. London: Alzheimer's Society.
- (4) Stokes, G. (2001) *Challenging Behaviour in Dementia. A Person-Centred Approach*. Bicester: Speechmark.
- (5) Bonner, C. (2005) *Reducing Stress-related Behaviours in People with Dementia*. London: Jessica Kingsley.
- (6) Pool, J. (2002) *The Pool Activity Level (PAL) Instrument for Occupational Profiling. A Practical Resource for Carers of People with Cognitive Impairment*. 2nd edition. London: Jessica Kingsley.
- (7) Benson, S. (ed.) (2002) *The Care Assistant's Guide to Working with People with Dementia*. London: Hawker.
- (8) VOICES (Voluntary Organisations Involved in Caring in the Elderly Sector) (1998) *Eating Well for Older People with Dementia. A Good Practice Guide for Residential and Nursing Homes and Others Involved in Caring for Older People with Dementia. Report of an Expert Working Group*. Potters Bar: VOICES.
- (9) McClean, W. (2005) *Practice Guide for Pain Management in People with Dementia in Institutional Care*. Stirling: Dementia Services Development Centre, University of Stirling.
- (10) McClean, W. (2005) *Facilitators Book for Pain Management in People with Dementia in Institutional Care*. Stirling: Dementia Services Development Centre, University of Stirling.
- (11) Cantley, C., Steven, K. and Smith, M. (2004) *'Hear What I Say', Developing Dementia Advocacy Services*. Newcastle upon Tyne: Dementia North, Northumbria University. Full text available free from: <http://www.dementianorth.org.uk>
- (12) Mental Capacity Act 2005 Summary. Department of Constitutional Affairs website: <http://www.dca.gov.uk/menincap/bill-summary.htm>
- (13) Cantley, C. and Wilson, R.C. (2002) *Put Yourself in My Place. Designing and Managing Care Homes for People with Dementia*. Bristol: Policy Press. Full text available free from: <http://www.jrf.org.uk/bookshop/>

Some useful journals:

The Journal of Dementia Care. Hawker Publications.

Dementia. The International Journal of Social Research and Practice. Sage Publications.

Nursing Older People. RCN Publishing Company.

Training resources

Darkness in the Afternoon. A short training video, with guidance notes for use, to get staff really thinking about the experience of someone with dementia. Available from Stirling Dementia Services Development Centre, cost £30 + p&p. See: <http://www.stir.ac.uk>

Make a difference in dementia care training. Training resource manual that includes 60 icebreakers, exercises and energisers with session plans, notes, diagrams and evaluation questions. Published by the Alzheimer's Society in association with Dementia Care Matters and available from the Alzheimer's Society, cost £70 + p&p. See: <http://www.alzheimers.org.uk/>

Oh Good Lunch is Coming. A cheerful and positive video showing examples of good practice in helping people with dementia to eat well. Available from Stirling Dementia Services Development Centre, cost £10 + p&p. See: <http://www.stir.ac.uk>

Positive Dementia Care. Distance learning programme aimed at giving all care workers the essential knowledge needed to offer the best professional approach to caring for people with dementia. Produced as a collaboration between Project Initiatives and Dementia Care Matters and facilitated by colleges around the country. ASET accredited and *usually* free. For more information contact Project Initiatives. See: <http://www.project-initiatives.co.uk/>

The Alzheimer's Society and the Dementia Services Development Centre at Stirling (see below) also provide training for trainers.

Organisations

Alzheimer's Society

Provides services and campaigns for people with dementia, their families and carers. Provides a wide range of information, fact sheets, resources, training packs and training on all aspects of dementia. Website also has lists of local branches.

<http://www.alzheimers.org.uk/>

Bradford Dementia Group

Provides undergraduate and postgraduate courses, including Dementia Care Mapping, research, resources and information.

<http://www.brad.ac.uk/acad/health/bdg/>

British Institute of Learning Disabilities

Works with policy makers, practitioners and people with learning disabilities to provide information, training, resources and support.

<http://www.bild.org.uk/>

Commission for Social Care Inspection

Launched in April 2004, the Commission is the single independent inspectorate for social care services in England. Its primary function is to promote improvements in social care.

<http://www.csci.gov.uk/>

Dementia Care Matters

Independent team specializing in working with organisations and their staff in developing dementia care services and mental health services for older people.

<http://www.demmatt.demon.co.uk>

Dementia Services Development Centres

These regional centres provide information and service development support on all aspects of dementia and dementia services. The following website provides access to DSDCs in England and also links to those in Ireland, Scotland and Wales.

<http://www.dsdcentland.org.uk/>

Department of Constitutional Affairs

Responsible in government for upholding justice, rights and democracy. Provides access to Mental Capacity Act 2005 information.

<http://www.dca.gov.uk>

Down's Syndrome Association

Provides information and support for people with Down's Syndrome and their families, carers and professionals; improves the knowledge about the condition; and, champions the rights of people with Down's Syndrome.

<http://www.downs-syndrome.org.uk>

The Leveson Centre for the Study of Ageing, Spirituality and Social Policy

Interdisciplinary centre that provides education, training, research and reflection, including a focus on dementia.

<http://rps.gn.apc.org/leveson/study.htm>

National Association for Providers of Activities for Older People (NAPA)

Provides a wide range of resources, training and workshops including specific developments for people with dementia.

<http://www.napa-activities.net/>

National Institute for Mental Health in England (NIMHE)

NIMHE, a part of the Care Services Improvement Partnership (CSIP), is responsible for supporting the implementation of positive change in mental health and mental health services. It works through regional development centres and its website provides access to a wide range of publications and resources.

<http://nimhe.csip.org.uk/home>

Wandering Network

An initiative set up by the universities of Northumbria, Edinburgh and Ulster and the Royal College of Nursing using evidence based practice to change values and attitudes and develop new ways of working that lessen the restriction on the autonomy of older people.

<http://www.wanderingnetwork.co.uk>

Personal and service development notes

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