

Responding to the pain experiences of people with a learning difficulty and dementia

Diana Kerr, Colm Cunningham and Heather Wilkinson

This report explores the pain management needs of people with a learning difficulty who have dementia.

People with a learning difficulty are living longer. This increased longevity brings with it the conditions and illnesses of older age, such as dementia. It is known that amongst people in the general population who have dementia there is inadequate pain recognition and treatment. This report has identified similar trends in pain management amongst people with a learning difficulty and dementia.

The report explores knowledge and practice in relation to pain recognition and management amongst direct support staff, members of community learning disability teams and general practitioners. It also examines the understanding and experiences of pain amongst people with a learning difficulty and dementia. It identifies the dilemmas and obstacles to effective pain management, and reports on examples of good practice. The authors make clear recommendations for practitioners and service providers.

The report found that the pain experiences and management of people with a learning difficulty who have dementia mirrored findings in relation to people in the general population. It did, however, identify extra and compounding issues in relation to people with a learning difficulty. The findings in this report will be of interest to service providers and direct practitioners in health, housing, social care and social work.



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1 Why question the pain management needs of older people who have a learning difficulty and dementia?

Aim of the research

The aim of this research project was to develop an understanding of the pain experiences of older people with a learning difficulty and dementia, and to explore the ways in which these are managed.

To meet this aim we followed five research objectives.

- 1 To identify the experience and expression of pain among older people with a learning difficulty and dementia.
- 2 To identify the experience and knowledge of support staff on the pain management needs of older people with a learning difficulty and dementia.
- 3 To examine the role of the community learning disability team (CLDT) and GPs in enabling effective pain care for people with a learning difficulty and dementia.
- 4 To establish what models of pain management exist to support older people with a learning difficulty and dementia.
- 5 To make recommendations and disseminate findings on models of pain management required to support older people with a learning difficulty and dementia.

Background

A number of studies have identified that the detection and management of pain in older people and people with dementia is a problem (Cook *et al.*, 1999; Main and Spanswick, 2000). The majority of these studies identified a range of issues that result in physical pain being inadequately treated in these groups (Clarke, 2000; Morrison and Sui, 2000). The detection of pain is documented as being poor (Kaasalainen *et al.*, 1998) and the treatment of this pain is found to be significantly

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lower than for the general population (Chibnall and Tait, 2001). Training and the use of appropriate assessment tools have been demonstrated to improve pain management (Edwards *et al.*, 2001), yet the level of training on this issue has been identified as inadequate (Sloman *et al.*, 2001).

Limited research has been undertaken on the pain management needs of people with a learning difficulty who have dementia, yet they will experience high levels of physical health needs that will, as a consequence, result in pain (Shronstein *et al.*, 2000; Walsh, 2001). The role of staff in the detection and management of pain is fundamental to it being effectively addressed. The inadequacies of staff training and practice to manage the pain care needs of older people and people with dementia appear to be mirrored in the field of people with a learning difficulty (Donovan, 2002). Ng and Li (2003) state that issues of a person's learning difficulty 'override and obscure physical illness' (Ng and Li, 2003, p. 12) and result in inadequate recognition and treatment of physical health needs, including pain. All the literature reviewed on pain and the needs of people with a learning difficulty focused on children and young people; there appears little recognition of the pain care needs of older people with a learning difficulty as well as those with both learning difficulties and dementia.

This study aims to examine the specific issues that facilitate or impede the appropriate identification and management of pain for an older person with a learning difficulty and dementia. The study began with an exploration of the perspectives of older people with a learning difficulty, which will inform an examination of actual practice within support and CLDT staff. The study then looked at determining what positive systems are in operation to identify and treat pain in older people with a learning difficulty, as well as what barriers exist to effective pain management. McClean (2000) has documented some of the primary obstacles to successful pain assessment and management. The key areas identified were used to form a checklist for exploring how well pain is managed. Recommendations are made on how to improve the pain care of older people with a learning difficulty and dementia.

Age classification of an older person

Studies are ongoing about the impact and onset of the ageing process on people with a learning difficulty. The majority of studies define older age existing in the adult with a learning difficulty when key factors associated with older age in the general population are present (Janicki and Dalton, 1998). Janicki and Dalton (1998) identify significant factors associated with premature ageing in people with Down's

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syndrome. For the purpose of this research adults with a learning difficulty over the age of 60 were eligible to participate, with the exception of people with Down's syndrome, for whom eligibility was from the age of 40.

2 Method

To ensure a rigorous examination of the pain care needs of older people with a learning difficulty and dementia the study took place over a 16-month period, from July 2004 to October 2005. There were four main phases to the research as outlined below.

Phase 1: listening to the views of older people with a learning difficulty about pain

In order to ensure that the main data collection phases for this study were informed by and grounded in the perspectives of people with a learning difficulty, this essential preliminary stage gathered the opinions of older people with a learning difficulty about their experience of pain. The data focuses specifically on exploring how older people with a learning difficulty understand and communicate about pain.

The findings from this preliminary phase were then used to inform the questions, vocabulary and methods used throughout the study.

Method for phase 1

Three sites were used for phase 1, determined because of ease of access and to provide a measure of geographical spread. In two sites one discussion group was held with older people with a learning difficulty. In the third site a discussion was held with one person. The consent process for this phase of the study was the same as used for the main phase 3 of the study described later. Each group had a maximum of six participants and they were asked questions on the subject of physical pain. In some cases pictures and word cards were used to facilitate the discussion.

The themes of the areas explored in the discussion group gathered data on the:

- participants' belief systems about pain
- words, phrases and non-verbal methods used to describe pain
- participants' views on the methods that they felt should be used to manage pain.

The data gathered through these group interviews was analysed thematically using a comparative coding system, and the findings were used to help us devise the questions and methods of communication used in phase 3 of the study when interviewing older people with a learning difficulty.

Phase 2: preparation for the main phase of data collection

Phase 2 was used to conduct a literature review, and to prepare all the materials and questions used to assist communication with people with a learning difficulty and dementia during phase 3. This preparation drew on the findings of phase 1 to ensure that vocabulary and ideas were familiar to this group. The questions for interviews with support staff were also prepared.

Accessing research sites

The main study used six research sites located throughout the United Kingdom. The reason for taking sites from throughout the UK was to take into account local and cultural aspects of communication, services and policy. While we aimed to identify specific locations that provided some sampling of the minority ethnic communities' experience of pain management, this was not achieved. The study sites were chosen for their size and geographical spread, and included residential and non-residential service provision.

Access to sites followed a detailed protocol based on the ethical procedures developed specifically for this study, drawing on recent experiences from a similar study (Wilkinson *et al.*, 2004). As part of the consent procedures information leaflets, consent forms and research protocols were all developed. The access route had three key stages:

- 1 identifying and making contact with sites and gaining management clearance to proceed
- 2 identifying and getting consent to participate from staff/advocate and relatives
- 3 identifying and getting consent from people with a learning difficulty who also had dementia.

Once approval had been given by the organisation for the site to be a case study, an initial telephone or face-to-face meeting was held with the site/service manager. This meeting was used to introduce the project, answer any questions and begin the process of identifying staff to be approached to participate. For participants from the community learning disability team (CLDT) a similar route was taken, first making contact with the team manager.

Information leaflets and consent forms were produced for staff, initially for use with the service manager and then again by the researchers to discuss the project, address any questions and initiate the consent process.

The service users were identified in collaboration with service managers. The potential participant or their advocate was then approached to request and seek agreement to participate.

Phase 3: main data collection

This phase involved the direct data gathering within the sites identified. The data were gathered from three primary groups:

- A older people with a learning difficulty and dementia
- B support staff
- C members of the community learning disability team and GP.

A Interviewing older people with a learning difficulty

Each individual with dementia was the central focus of a case study and, where it was possible, interviews or guided conversations were held with each case study participant. Time was also spent observing each person in their 'home' setting. The inclusion criteria for inviting participants to take part were that the:

- 1 person has a medically diagnosed or suspected dementia
- 2 participant meets the age criteria for the study.

Interviews were conversational, observational and informal in their nature. The themes of the questions asked of participants were:

- their belief systems about their pain
- the words, phrases and non-verbal methods they use to describe their pain
- their view of how their physical pain is managed
- their view of how their physical pain should be managed

B Perspective of support staff

As support staff have a crucial role to play in ensuring that the pain care needs of residents are met (Morrison and Siu, 2000), the opinions of staff within the settings of participants with a learning difficulty and dementia were sought. Group interviews containing a maximum of six staff in each group were held in each site. The group interviews focused on the same themes as those for participants of older people with a learning difficulty:

- the participant's belief systems about pain
- the words, phrases and non-verbal methods they observe older people with a learning difficulty and dementia using to describe their pain
- the participant's view of how the physical pain of older people with a learning difficulty and dementia is managed
- the participant's view of how the person's physical pain should be managed.

C The role of the community learning disability team and GP

The community learning disability team (CLDT) has a key role in supporting people who have a learning difficulty (Scottish Executive, 2000; Department of Health, 2001). It was, therefore, important to consider their views on the issues relating to the effective management of pain in older people with a learning difficulty and dementia.

A CLDT was interviewed in each of the study locations visited. A group interview context was used and it was aimed to have the following members of the team present: the team leader/consultant, the psychologist and the community learning disability nurse. Each group contained a maximum of six team representatives. In each location at least one GP was also interviewed in a one-to-one interview.

These group interviews contained the same themes as those used for participants with a learning difficulty, with the addition of questions on what collaboration is undertaken with other disciplines and agencies on the issues of client/patient pain management?

Phase 4: data analysis

The data, both from the interviews and focus groups, were collected using audio tape recordings and these were transcribed as quickly as possible. The thematic analysis of verbatim transcripts was also supported by notes of observations and reflections made by the researchers immediately following interviews. Analysis of the data was an iterative process and overlapped the period of interviewing. A collaborative approach was taken with research team members carrying out a detailed review of specific transcripts and then identifying key themes, concepts and processes emerging from the data. The team then looked at these themes again to understand more fully the similarities and differences in the respondents' accounts (Lofland and Lofland, 1995).

People interviewed

Tables 1 and 2 provide a breakdown of the people interviewed and observed during this study.

There are a number of case studies given throughout this report. Some are based on people interviewed, some on people observed and others from staff reports. Every effort has been made to ensure that confidentiality and anonymity have been maintained.

Table 1 Breakdown of total numbers of people interviewed

People interviewed	Number
Support staff	49
Psychiatrists	2
Psychologists	3
Managers	12
GPs	6
Community nurses	6
Occupational therapists	2
People with dementia	6
Total number of interviews	86

Table 2 Breakdown of people with a learning difficulty interviewed and/or observed

Pseudo name	Gender	Age	Down's syndrome (DS) other learning difficulties (LD)	Observed (OB) or interviewed (IN)
Keith	Male	52	DS	IN
Wendy	Female	50s	DS	IN
Maureen	Female	72	LD	IN
Patrick	Male	47	DS	IN
Colin	Male	53	DS	IN
Charlie	Male	52	DS	IN
Freda	Female	70	LD	OB
Diane	Female	54	DS	OB
Betty	Female	52	DS	OB
Roger	Male	53	DS	OB
Oliver	Male	60s	LD	OB
Una	Female	50s	DS	OB
			Total	12

Roger: case study 1

Roger is a man with Down's syndrome with a diagnosis of dementia.

He is described by staff as being a 'determined' man used to 'getting his own way' and not averse to being a 'bit awkward to achieve what he wants'.

Roger is seen as a man who presents 'challenges to others'.

He has a number of health-related problems that could be causing him pain.

He has few teeth. The ones he does have are in a poor condition. They are wobbly and indeed they have started to fall out. Recently, one was found on his pillow in the morning. The dentist 'feels they have been causing him some discomfort' (staff). Roger often refuses to eat. Staff recorded that 'every morning before I give him breakfast he will say "my head hurts and my eyes"' (staff).

The staff who support him agreed, when asked, that he might have painful gums.

Roger also has very sore eyes, which are prone to infection. They are dry, they bleed in the corners and he constantly rubs them. Sometimes he will poke them with objects in what appears to be an attempt to scratch them.

Roger has cream to moisten his eyes and reduce the irritation. This comes in a tube that has a special nozzle to apply it to the eye. This should remove the need for direct contact with the hand and the risk of introducing infection. Despite this, a member of staff was observed applying this cream with their finger, having just come from a bathroom where the hand towel was less than sanitary. Roger's eyes were noted by the GP to be reinfected regularly.

Roger also wakes at night and swears and curses. Sometimes he bangs his head on the wall in his bedroom, 'his sleep disturbance is one of the things that we struggle with most' (staff). In fact, staff stated to the researchers that Roger's night time disturbances, which they related to the impact of his dementia meant that they were considering moving him to another setting where he would not disturb the other tenants and where there would be waking night staff.

Roger does not receive any pain relief.

This case study highlights a number of issues that are addressed in this report:

- attributing all changes to the impact of dementia – diagnostic overshadowing
- a history of behaviour that is perceived as 'challenging'
- this history influencing present assessments
- staff not thinking about pain

(Continued)

- inadequate pain relief
- prevalence of dental problems in older people with a learning difficulty
- prevalence of eye problems, particularly in people with Down's syndrome
- the need for staff to be aware of their role in maintaining good health.

3 Factors that contribute to problems with pain recognition

The existence of a high level of unrecognised and, therefore, untreated pain among people with dementia in the general population (McClellan, 2000) is likely to be replicated among people with a learning difficulty (Wilkinson *et al.*, 2004).

It is, perhaps, not unreasonable to suggest that people with a learning difficulty and dementia may fare even less well than their non-disabled counterparts. There are a number of reasons that might support this:

- 1 diagnostic overshadowing
- 2 prominence within the service of people with behaviour that challenges
- 3 the past experiences of many people with a learning difficulty
- 4 the employment of agency/bank staff
- 5 communication difficulties
- 6 beliefs about pain thresholds.

Diagnostic overshadowing

There is evidence that the fact that someone has a learning difficulty can often 'override and obscure physical illness' (Ng and LI 2003, p. 12). It is also recognised that within the general population of people with dementia there is a tendency to attribute changes in the individual to the progression of their dementia, rather than other causes (Mason and Scior, 2004). There was evidence in this study that people with both a learning disability and dementia experienced the impact of both these responses leading to diagnostic overshadowing.

Now that you have made me think about it I realise that I had thought that the changes in his behaviour was because of dementia and now I think;
'What if it's pain?'
(Manager)

Prominence within the service of people with behaviour that challenges

People with a learning difficulty, for a variety of reasons, more often present with behaviour that challenges their carers and services than their non-disabled age-matched peers (Meyer and Evans, 1994). Indeed 'challenging behaviour' is often given high priority among training courses for staff working with people with a learning difficulty. While this is a vital aspect of staff learning and skill development it presents a problem for staff and people with a learning difficulty when they develop dementia, and in particular when the person with a learning difficulty develops pain.

If someone already has a history of behaviour that others find challenging it is often difficult to determine if the behaviour exhibited is a repeat of previous behaviour, a new behaviour that is not pain related or a behaviour that may be caused by pain. If staff are primed to interpret behaviour as challenging they do not readily consider other potential meanings, such as it being a response to an experience of pain:

I think it's seen as behaviour before pain.
(Manager)

She's very challenging, physically aggressive, verbally aggressive. I've been told that if she's in so much pain she wouldn't be able to lash out ... I've been told that by a physiotherapist ... it is just seen as challenging behaviour.
(Staff)

Two [of the] men have very challenging behaviour. You would have to think was it learned behaviour?
(Staff)

The implication here is that the meaning of the behaviour is to do with previously learned responses and not necessarily a reaction to pain. The label of 'challenging behaviour' can override other considerations in a way that it might not if 'challenging behaviour' was not such a prominent issue within the learning disability service.

This priming to consider 'challenging behaviour' as 'behavioural' is compounded by the way in which challenging behaviour is often also seen as an inevitable aspect of dementia (Stokes and Goudie, 1990). The inclination to see the behaviour as caused solely by the dementia ignores the fact that pain is positively associated with screaming, aggression and verbal agitation in dementia (Cohen-Mansfield *et al.*, 1990). The misinterpretation of the meaning of the behaviour is compounded by the

fact that, despite discouragement to do otherwise, the primary response to 'challenging behaviour' in people with dementia is treatment with antipsychotic medication (Elenchenny and Shah, 2001; Balfour and O'Rourke, 2003). The use of antipsychotic medication could mask symptoms related to pain and therefore make the identification of the pain more unlikely (Kovach *et al.*, 1999).

Past experiences

The way in which people respond to pain is determined by a number of factors: ethnicity, gender, social class, urbanisation and age can be significantly influential (Skevington, 1995). All these will contribute to a person's history of and response to pain. For people with a learning difficulty these factors are overlaid by other contributory factors. Many people with a learning difficulty will have experienced a particular and peculiar culture because of their experience of institutionalisation. This may be a significant contributing factor to the way they experience and exhibit pain.

Many people who are now older have lived through a period when attitudes to and treatment of people with a learning difficulty were often institutionalising and sometimes insensitive or even cruel (Goffman, 1961; Miller and Gwynne, 1972; Sinson, 1993). This has left many people with anxieties about being mistreated or ignored, as evidenced later in this chapter and elsewhere in the report. This is particularly an issue when someone develops dementia. Added to the memory of past experiences is the consequence of the changing realities of the person with dementia.

As the condition progresses and the person's short-term memory is increasingly damaged and depleted, the reality for the person is based increasingly in their past. This can lead to the growing and certain belief that the person is actually back in the place they lived in for much of their life. This may have been an environment where pain was not well acknowledged or where, when treated, was not done sympathetically.

During this research study we heard many examples of past experiences that may have led people to deny their pain experience for fear of possible consequences or because they thought that they would be ignored:

They have been in the system so long. They get institutionalised and they don't know how to express themselves ... or they might think there is no point in reporting pain.

(Manager)

The history of Katie is that she has never been one to like medical staff ... scared her a lot, she associates hospitals with examinations, needles and [unpleasant] staff.

(Manager)

This fear of mistreatment was explained in another setting when a staff member, who had worked in a long-stay hospital, recounted a story of a man who had probably been in pain and started to scream. He was 'hosed down and had his possessions thrown out of the window' (staff).

The present fear of complaining about painful experiences that would lead to involvement with dentists and doctors was explained in relation to one man who, as a teenager, had complained of toothache. A visit to the dentist resulted in all his teeth being removed. Staff felt that this explained not only his morbid fear of dentists, medics and needles but also his assertion whenever asked about pain that 'I'm alright'. This example underlines the importance of the development of good life-story work before someone develops dementia. Life-story work can mean that 'a significant amount of previously unknown information about people is discovered' (Kerr and Wilkinson, 2005). Vital information about the person's past helps to explain their present behaviour.

The possibility that people have learned that there is no point in complaining about having pain as this was sometimes ignored was partially explained by the following comments from two different members of staff who have both worked in a long-stay hospital:

There was too much going on to be able to give much attention to one person.

(Staff)

In the old days ... it was a matter of suffering in silence.

(Staff)

It would be irresponsible to suggest that the above has been true of all or maybe most people with a learning difficulty, but it is certainly a possible explanation of some responses for some people.

Age may also be a contributory factor. Many people with a learning difficulty, and particularly people with Down's syndrome, will have lived with their parents for their adult as well as their younger lives. This means that they may often carry the attitudes of their parents rather than of their peers. This may well include attitudes to

pain that are more stoical than those of their non-disabled peers. This could result in the person not complaining about pain as often as might be expected in someone age matched in the general population.

Employment of agency/bank staff

The impact of the employment of agency/bank staff on the process of pain recognition was highlighted. A critical component in the recognition of pain was the extent to which staff had an understanding and knowledge of the person with dementia. It was evident that, where staff were not familiar with the person with dementia, they were often unable to recognise behaviours that might have related to possible pain:

Having agency in ... they're not looking at the big picture.
(Staff)

You have to know the person.
(Staff)

All these things [the pain indicators] would not have been picked up if we had not known the person.
(Staff)

All organisations that took part in this study were hesitant about using bank/agency staff. When they did use them they used only regular bank staff who were familiar with the people they supported. Some staff struggled to cope without the extra staff because they recognised the problems this caused in relation to many areas of work, including pain recognition.

Communication difficulties

Pain is a highly subjective experience. Many things influence how an individual will experience pain, as indicated in the earlier section on past experiences. The person with the pain is the only one who knows how bad or enduring it is. Others have to ascertain this through observation and communication. This, of course, presents a problem when trying to assess pain in a person with dementia.

One definition of pain is that:

Pain is whatever the patient says it is, and occurs whenever the patient says it does.

(McCaffery, 1968, p. 95)

But what if the person cannot say? The onset of dementia means that people begin to lose their ability to communicate. Many people with a learning difficulty have problems with communication anyway. It is estimated that at least 50 per cent of adults with a learning difficulty have significant problems with communication (Department of Health, 1993). This is exacerbated by the onset of dementia.

They start to lose the few words they have that might help them to describe the pain. Indeed, even within the general population, verbal communication about pain is diminished in frequency and intensity when people develop dementia (Farrell *et al.*, 1996). It is not unreasonable to expect this same decline among people with a learning difficulty. It may well be that, because they have fewer words to start with, the impact of the loss of vocabulary leaves them at a greater loss than the general population earlier on in the development of the condition. People supporting individuals with a learning difficulty and dementia cannot rely on the use of words, nor indeed on their own experience and understanding of pain behaviours.

Furthermore the onset of dementia results in the part of the brain that holds an understanding of the geography of our body being damaged (Kerr, 1997). This means that the person has difficulty and eventually is unable to indicate the part of the body where the pain is being experienced:

She will point to other areas, she will point to her stomach or her head and it is really her mouth.

(Staff)

They can neither say the words 'I have toothache' nor point to or hold the part of the body where the pain is, holding their jaw, for example, for toothache:

We used to know him quite well ... he would let you know his immediate needs ... now he has dementia it's really hard to know when he is in pain.

(Staff)

The difficulty with understanding and using language makes asking direct questions problematic:

Problems with pain recognition

We can't ask directly 'have you got a pain?' because they say 'no' but then that does not mean they do not have a pain. It may mean they do not understand the question or they say yes and it is always yes so you are no further forward.

(GP)

Additionally, the use of alternative forms of communication such as Makaton® becomes problematic. This and other forms of sign language require a sense of the geography of the body. Clearly, once the part of the brain that contains that information is damaged, then the use of these forms of communication is diminished:

She used to use Makaton® ... and then all of a sudden she stopped using it.

(Staff)

Sometimes the person will use a phrase as a substitute for more accurate and direct indications of pain:

He says 'oh dear, oh dear' [when he is in pain] ... he didn't used to say that.

(Staff)

An example would be Roger who had such terrible gum disease that his teeth were falling out. He never referred to his teeth but simply said 'My head hurts'.

Of course, many of these communication issues could also apply to people without dementia. The issue for the research reported here is that people who previously could communicate their pain needs effectively lost the ability and, of course, for people who always had problems, the difficulty was exacerbated.

Belief about pain thresholds

The belief that people with a learning difficulty have a high pain threshold was often expressed in this study. This belief means that staff are not necessarily disposed to interpret behaviour as the result of pain if they believe that the person is not as likely to experience pain to the same extent or intensity as non-disabled people:

Their pain threshold is so high that sometimes you can have behavioural problems before you realise that it's actually pain that they're suffering from.

(Staff)

A great percentage of people with learning disabilities also have extremely high pain thresholds.

(Staff)

Individuals who we would find have a higher tolerance of pain would be people with autism.

(Community nurse)

People do have different pain thresholds (Skevington, 1995). Within the general population, as indicated earlier, there are variations in the way people experience and acknowledge pain. However, these are individual responses and should not inform our readiness to dismiss or consider the existence of pain.

Even a study that does suggest that a few people with Down's syndrome may have a higher pain threshold emphasises the point that:

Some of the apparent pain tolerance may be due to our inability to interpret the complaints of some people with Down syndrome.

(Chicoine, 2002, p. 2)

If staff and other people involved with people with a learning difficulty and dementia are going to recognise pain behaviour then they need to be aware of the possibility that it exists. They also need to know the type of behaviours in each individual that may indicate pain. They also need to be aware of the past experiences of the person that might mean they deny the existence of pain.

Keith: case study 2

Keith is a man with Down's syndrome and a diagnosis of dementia. He is in his early fifties.

Keith has a severe back problem. He is often seen shaking and unable to walk because he is in so much pain from spasms. However, when he is asked 'Keith is your back hurting?', he replies 'no I'm alright' even though he is unable to walk.

He is also reported as sometimes having diarrhoea and sickness. He 'would be vomiting into a bucket' while also telling staff that he is fine and there is nothing wrong with him.

(Continued)

This man was described by some staff as ‘having a high pain threshold’ (staff). So, despite Keith displaying pain-related behaviour (‘unable to walk’), the staff take his statement ‘I’m alright’ at face value. They explain this in terms of Keith having a high pain threshold.

Undoubtedly, people with a learning difficulty, like their non-disabled counterparts, will have individual and different responses to pain. If these differences get exaggerated and generalised to the whole population with learning difficulties, this will reduce sensitivity to the possibility that someone might be experiencing pain.

Summary

The existence of a high level of unrecognised, and therefore untreated, pain among people with dementia in the general population (McClellan, 2000) is likely to be replicated among people with a learning difficulty (Wilkinson *et al.*, 2004). It is also probable that the levels of pain recognition may be poorer for people with a learning difficulty and dementia than among the non-disabled population.

There are a number of factors that contribute to pain not being sufficiently recognised among people with a learning difficulty and dementia. The prominence within the service of people with behaviour that challenges means that staff are often primed to see ‘challenging behaviour’ as ‘behavioural’ rather than having been triggered or influenced by a factor, such as pain. Our life experience influences our response to pain. Many people with a learning difficulty will have had negative experiences in relation to pain recognition and treatment. This will sometimes mean that people deny their pain experience for fear of possible consequences or an expectation that they will be ignored. People with a learning difficulty and dementia have difficulty communicating their pain experience and needs. This makes it difficult for everyone to understand the meaning of their communication. This can be exacerbated by the employment of agency/bank staff who are not familiar with the individual, and can result in key information about the person’s pain behaviours and expression not being understood and responded to. A further barrier to pain recognition is the generalised but concerning belief that people with a learning difficulty have a high pain threshold.

Recommendations arising from this chapter

- 1 There must be training on pain recognition for all staff involved with the care, support and treatment of people with a learning difficulty and dementia. The curriculum must address a number of issues including the:
 - subjectivity of pain experiences
 - communication problems caused by the onset of dementia and how these might hinder pain recognition
 - need to consider the possibility that behaviour that challenges may indicate the existence of pain.
- 2 There should also be training about *behaviour that challenges*, which must include training about the way in which dementia affects people and the consequent changes in the meaning of the behaviour.
- 3 Furthermore, training on *behaviour that challenges* must include recognition of the possibility that it may be caused by pain.
- 4 There must be a cautious use of agency/bank staff. Staff used from this source must receive the same training on pain recognition as other staff.
- 5 Life-story work must be developed as an essential tool to enable staff to understand the person's past in order to understand their present behaviour. This should preferably be developed for everyone before they develop dementia.

Overall recommendations are listed in the Appendix.

4 The experiences and views of people with a learning difficulty and dementia on pain management

Geoffrey: case study 3

Geoffrey was a man with Down's syndrome and dementia. He had lost all his teeth many years ago and ever since had successfully worn dentures without any complaint.

A while after the onset of dementia he started to take the dentures out and would try to hide them. Staff kept giving them back and, with instructions from the most senior worker, insisted that Geoffrey wear them. He would again take them out and try to hide them. This went on for some time with Geoffrey becoming more and more distressed at mealtimes when there was insistence on him wearing the dentures. No attempt was made to investigate his gums or to figure out the meaning behind the changed behaviour.

One day his dentures had completely disappeared. In conversation a student working in the house commented that she had seen, to her amazement, Geoffrey up at the top of a tall tree in the garden. An investigation of the treetop revealed Geoffrey's dentures.

An investigation of his mouth revealed painful gum disease.

Clearly, Geoffrey had been trying to communicate, but, in the end, took things into his own hands and placed the dentures as far away as he possibly could. It is important to again acknowledge that people with a learning difficulty and dementia are going to have problems with communication, but perhaps we should do something before they reach the need for such dramatic and desperate actions. Undoubtedly, Geoffrey was giving his views on the lack of pain management. This chapter seeks to get some people's more direct views.

There has been an increasing volume of research that explores the views and experiences of people with dementia (Kitwood, 1997; Allan, 2001; Wilkinson, 2002). There has also been an increased attention paid to the views and experiences of people with a learning difficulty who are growing older (Ward, 1998). There has been scant research attention paid to the views and knowledge of people with a learning difficulty and dementia (Stalker *et al.*, 1999). In this study we sought to redress the

balance by giving some people with a learning difficulty and dementia the opportunity to tell us about their views and experiences of pain. Six people were interviewed. We have also drawn on our direct observations of six other people (see Table 2 in Chapter 2 for further details).

With the exception of one man, everyone either exhibited pain behaviours and/or described them. It should be noted that most, but not all, of the people interviewed still had the ability to communicate fairly well. They are not, therefore, representative of the many people with a learning difficulty who have communication difficulties prior to the onset of dementia, nor of people who have a more advanced condition. As described in Chapter 3, as the condition progresses, people will have increasing difficulty describing the pain, its location, duration and type. We were fortunate, therefore, to have the opportunity to talk to the people quoted below who were still able to articulate their needs and experiences.

It is significant that there were other people who were living in some of the study sites who may well have been able to articulate their pain needs to the researchers. However, the researchers worked with individuals with whom they were already familiar and this eased communication. For other potential participants, it was felt that the researchers were not well known enough to the people and were therefore not sufficiently familiar with their methods of communication. The importance of familiarity to support good communication, in this case between researcher and research participant, to an extent served to reinforce findings given in other parts of this report on the importance of staff knowing the person and the difficulties caused by the use of agency staff who, like the researchers are not familiar to or with the person who has dementia.

The need to have trust as well as understanding was reinforced by the responses from the people quoted in this chapter. The people who provided the most information were often already well known to the researchers.

This is a small qualitative sample. The data gathered provided valuable and relevant information towards our understanding of some of the needs and experiences of people in relation to pain.

The themes that emerged from the interviews and observations were:

- 1 the acknowledgment of type of pain
- 2 strategies used to alleviate pain

3 night-time pain

4 the role of seating in pain experience.

The acknowledgment of type of pain

Unlike many people with a learning difficulty and dementia (Wilkinson *et al.*, 2004), the people here were able not only to acknowledge their pain but also to find words that indicated its location and type:

I sometimes get a pain in my leg and you hear the bones cracking.
(Woman with dementia)

Get it there, my hip I can't lie on that.
(Woman with dementia)

Yes, pain in back.
(Man with dementia)

The type of pain described most commonly seemed to be arthritic pain. This confirms the pain described most commonly by staff. Arthritis is, of course, a condition generally associated with older age (Hicks, 1999). It is not unexpected, therefore, that people over the age of 40 years with Down's syndrome and people over the age of 60 with a learning difficulty for reasons other than Down's syndrome are experiencing notable levels of the condition (Janicki *et al.*, 2002):

I get arthritis in my knee and they crack.
(Woman with dementia)

It sore ... it hurts me [a swollen leg joint].
(Woman with dementia)

My neck ... well I get arthritis in there.
(Woman with dementia)

Other pains that were highlighted included examples of abdominal pain:

I get pain here [points to tummy].
(Man with dementia)

I am not happy when I get tummy ache, diarrhoea.
(Man with dementia)

Strategies used to alleviate pain

Of great interest were the various strategies that people had for dealing with their pain. One lady who had painful arthritic knees described how she 'put my foot on the cold floor and let it stay there for a while ... I stand for a while until the pain goes away'.

I lie flat out and I'm alright.
(Woman with dementia)

As with many older people in the general population some people had a stoical view of their need for pain relief:

I just put up with it.
(Man with dementia)

No I never take painkillers. No never in my life.
(Woman with dementia. It needs to be stated that in fact this woman did take painkillers but seemed to think it was not a good thing to do)

Night-time pain

The descriptions given of the ways in which pain affected the sleep patterns of people with dementia were of great interest and concern. Lying in one position for long periods exacerbates many conditions. People with arthritis will stiffen during the night (Cook *et al.*, 1999). Turning over can be painful and will cause people to wake. Once awake they will often find it hard to return to sleep.

It is important to emphasise that sleep disturbance is more common among people with dementia (Fetveit and Bjorvatn, 2002). People with Alzheimer's disease and people with Lewy Body dementia have been found to have specific changes in their circadian rhythms, which can result in significant sleep disturbance (Grace *et al.*, 2000; Volicer *et al.*, 2001; Cole and Richards, 2005). Most older people do wake at night because of sleeping difficulties (Martin, 2000) but the disorientation in time and space caused by the dementia means that, when people with dementia wake, they

are often distressed and confused. The confusion will often mean that they mix up day and night. They will become agitated and worry that they are going to be late for the day's activities, going to the day centre, to work or simply getting their breakfast. Other things can exacerbate this, for example the presence of mirrors in the bedroom. The person may see reflections in the mirror, which cause them to think that other people are in the room (Kerr, 1997).

It has to be of concern that people are being woken up during the night by pain. Apart from the unacceptable pain experience, it is also exacerbating the sleep problems associated with dementia. The following descriptions of night-time pain illustrate very well the reasons why staff need to be vigilant about night time pain relief:

Well it swells if maybe I'm lying in bed sleeping and I wake up stiff.
(Woman with dementia)

So do you get pain in your knees most nights?
(Interviewer)

I do yes, definitely, yeah.
(Woman with dementia)

My hip [hurts] ... I can't lie on that, I feel it in bed.
(Woman with dementia)

I have to put up with it when I am in bed, but I can't sleep.
(Man with dementia)

The woman quoted earlier describing how she put her foot on the cold floor said that she did this mostly at night.

Some of the people interviewed were also able to recount ways in which their night-time pain was dealt with by staff:

I would say 'if you are not too busy can you give me pain killers?'
(Woman with dementia)

Sometimes when X is sleeping [sleepover staff] she says 'you ask if you have pain when I am on night duty'.
(Woman with dementia)

Do you take anything at night for your sore knees?

(Interviewer)

Now and again to help the pain in my legs ... I get cramp there.

(Woman with dementia)

I get tummy ache at night, here [rubbing front] I wake up got tummy ache ... I put up with it.

(Man with dementia)

However, when asked about this man's pains and in particular about the possibility of pain at night, the staff did not consider that he had pain.

Of course, what is significant about the quotes given above is that the people were still able to articulate their pain and sometimes also to ask for pain relief. Most people with dementia would not be able to do this; indeed many people with a learning difficulty even without dementia may not be able to do this (Donovan, 2002). This must lead to concern for the amount of night-time pain and discomfort that people might be experiencing, which causes them to wake and perhaps to present with 'challenging behaviour', which may be misinterpreted as 'just part of the dementia'. In the general population this misdiagnosis can result in poor treatment (Tsai and Chang, 2004; Molony *et al.*, 2005).

Of concern was the fact that people had to ask for pain relief even when they seemed to have pain every night. It appeared that analgesia was not being prescribed to help them, either through the night, or prior to the person getting up in the morning when the pain and stiffness from arthritis made the morning routines especially painful. Recommendation on pain management would suggest that regular analgesia instead of 'as required' (PRN) analgesia may have been more effective in these situations (SIGN, 1998; NICE Guidelines, 2004).

The role of seating in pain experience

While night-time pain that woke people was clearly articulated, the pain caused during the day by inappropriate seating was more commonly observed than stated. The seating provided failed to take account of the changing physical needs of the older person. There were particular issues in relation to people with Down's syndrome, which are described in this chapter.

One woman talked about the need to have not only her bed but also her chair flat so that she could have her leg 'straight out' and also not to be in a sitting position that hurt her hip. The importance of being aware of the angle at which people were sitting and the appropriateness of the furnishings themselves was made also in relation to people observed by the researchers.

People with arthritis and other painful conditions, and indeed people who are unable to adjust their own seating and sitting position, are vulnerable to potential pain experiences if they are not supported well.

As far as is possible, services for people with a learning difficulty provide ordinary housing and ordinary non-institutional furnishings. During this study people with Down's syndrome and dementia were observed lying at an uncomfortable angle in their seats, as they had slipped down them. This was usually because the seats were too high from the ground and people were unable to place their feet flat. This is a particular issue for people with Down's syndrome because of their shorter leg length (Kerr, 1997). Even special supported seating may not be adequate. It may not prevent them from slipping down into uncomfortable and unsupported positions with their backs being uncomfortably arched as a consequence. Additionally, the chairs observed did not provide the type of support that people with dementia require as they lose the ability to support their bodies themselves.

Unfortunately, the pain was often picked up only when the person started to groan or move about in a way that indicated possible discomfort. The researchers also observed examples of hoists being used to manoeuvre people back into a sitting position. This was a frightening and perhaps unnecessary procedure, which may have been avoided if the correct seating had been provided.

Summary

It is important to emphasise the fact that the people interviewed were generally able to articulate their distress and pain and so more able than many to elicit pain relief. They were, however, still not getting adequate pain relief either in the form of analgesia or from non-drug interventions. One area where there was untreated pain, which caused particular concern was pain experienced at night. This exacerbates the night-time waking, which can be a characteristic behaviour of people with dementia. This is an issue that all staff must address. In order to reduce pain caused by poor positioning there is a need for attention to be paid to the provision of supportive and, where required, individualised seating. There is a particular need to

consider this in the context of people with Down's and other syndromes where people may have a shortened stature.

Recommendations arising from this chapter

- 1 Staff must actively facilitate the communication of pain by people with a learning difficulty and dementia.
- 2 'As required' (PRN) analgesia should not be the primary approach to pain management in people with a learning difficulty and dementia. Analgesic prescription must follow the World Health Organisation Guidelines on prescribing (WHO Guidelines, 1996). These recommend regular administration and also that treatment should be adjusted from one step to the next according to increasing or decreasing pain severity, history of analgesic response and side-effect profile.
- 3 Staff must recognise that people with a learning difficulty and dementia may be waking at night because of pain and not just because they have dementia.
- 4 Staff must consider the administration of night-time analgesia for pain management.
- 5 The provision of supportive individualised and adaptive seating needs to be given a higher priority.

Overall recommendations are listed in the Appendix.

5 The knowledge, experience, role and views of staff in relation to pain management

The staff referred to in this chapter were mostly support staff working directly with individuals. Some were supporting people in single tenancies, others in small groups of three to four people and some in larger groups of up to 15. Two staff were supporting people in a nursing home setting. In total 49 direct care/support staff were interviewed.

It needs to be emphasised that staff who took part in this study were very often working under great pressure. People were frequently struggling to maintain high levels of support and service to enable people with dementia to remain at home. Obviously, under these circumstances, it is likely that attention to some of the pain indicators in the people they support might be overlooked. It is within this context that the following should be viewed.

The key themes that emerged were the:

- 1 need for increased staff awareness about the existence of pain among people with dementia
- 2 role of staff in pain recognition
- 3 importance of staff observation and information as part of the doctor's assessment process
- 4 lack of any formal assessment tool or process
- 5 administration of medication for pain relief
- 6 role of non-pharmacological interventions.

The need for increased staff awareness about the existence of pain among people with dementia

There was evidence throughout the study that, although pain was sometimes considered in relation to people with dementia, staff were not sufficiently conscious of pain as a possible explanation for behaviours. This is not to suggest that staff were insensitive. It is an observation that, among all the things they had to consider, pain was not given sufficient recognition or priority. Possible explanations for this are discussed in Chapter 3.

The need to raise the level of awareness about the possibility that people with dementia may be exhibiting behaviours that were the result of pain experiences was underlined by the impact on staff knowledge and awareness as a result of taking part in this study.

It was noteworthy that, in many of the sites, when the researchers returned after the initial information and consent process had been undertaken, the staff had started to discuss the possibility that there might be greater pain among the people they supported than had previously been acknowledged. In a number of sites, individuals had actually been identified as being in pain when this had not been considered or diagnosed prior to the research involvement:

Since we have taken part in your research we are offering pain relief to our residents ... then we discovered that this was her problem.

(Manager)

But until I had my conversation with you [the researcher] ... I didn't think pain, just dementia.

(Staff)

I did some service design recently, one of the things I wrote was 'don't forget the physical pain'.

(Manager)

Was that after I started to talk to you about the research?

(Researcher)

Yes.

(Manager)

These findings are encouraging. They suggest that there is a need for a greater amount of awareness raising and training for staff. It also indicates the commitment of staff to take on new ideas.

The role of staff in pain recognition

Chapter 3 described many factors that result in pain recognition among people with a learning difficulty and dementia being problematic. Nevertheless, these problems need to be overcome by staff if people are going to have their pain needs met. Staff play a critical role in the detection and management of pain (Regnard, 2003), as the critical part of pain assessment is that a person's behaviour is understood in terms of both their previously known behaviours and their personality and interaction with others. Staff clearly play a vital role in understanding both these areas.

In many sites there were a few staff members who had known the person they were supporting for many years, in some instances for up to 15 years. This did make a positive difference to their understanding of the person they were supporting and make it more likely that they would pick up on pain behaviours. In all sites, however, there were newer staff who did not have such a substantial history with the individual. Equally important as the length of the relationship, however, was the nature of the present relationship. Staff were often intimately involved with people. They were aware of the various idiosyncrasies and foibles that are known only to people who have close relationships.

The importance of this information and knowledge was made clear when staff described reasons that made them think someone might be in pain:

You get to know people when you are working with someone so closely like that, you get to know ... you get little looks and you know exactly when something's not right, it's picking up those tell-tale signs, it's knowing that person's tell-tale signs.
(Staff)

This resonates with work carried out by Regnard *et al.* (2003, p. 1), which stated that 'the recognition of distress cues is an intuitive rather than a conscious act'. In the example given above, the staff member was picking up on changes that were hidden to the researchers. She seemed to *feel* as much as *see* the changes.

Other examples of this use of 'feeling' as much as concrete 'seeing' were given throughout the study:

You just know she is not well, you just go through it with her.
(Staff)

She seems unhappy and I think she is in pain then.
(Staff)

What was interesting was that the staff could not always be specific about what it was that made them think the person was unhappy; it was a feeling, a sense of unhappiness. Underpinning all of this, of course, is an attitude of attentiveness to minute changes that might indicate pain. Such a level of observation has to be close and maintained with a constant alertness to the possibility that someone may be experiencing pain (Chatten, 1995):

She does not have much speech, but you could tell from her body language that she was in pain.
(Staff)

Well her face, her expressions, the way she is sitting.
(Staff)

Yeah for some people, particularly with people known before the experience of dementia, we might have an idea, know some of the communication signs.
(Staff)

She could never really articulate if she was in pain, but her behaviour would change, she might pace up and down more.
(Staff)

Well there are some things that are fairly obvious that you can see as a source of pain. He broke his hip a couple of times and you can see he's getting stiffer now so you think 'oh that must be painful' but you don't know what times of day it is particularly painful, he does shout out a lot.
(Staff)

This final quote serves to underline two important factors. First, that it was important that the staff member knew about the man's history; second, that, even in knowing this, it was hard to determine when the pain was at its worst, and what was pain and what else might cause him to shout out.

Staff were able to observe changes that were sometimes only obvious to someone who knew the person well:

How do you gather information about whether X is in pain?
(Researcher)

It's her eyes isn't it ... sad little eyes?
(Staff. This was in reference to a lady who had a urinary tract infection)

This particular observation underlines the need for staff to have time as well as sensitivity to the possibility that someone might be in pain. If staff are busy and rushing they may well miss the more subtle changes. This need to pay attention to subtle changes is illustrated in case study 4 by a particular observation made by a staff member when the researchers were present.

Freda: case study 4

A lady was sitting in her chair. She was still and silent, occasionally sleeping but there was little communication beyond a smile every so often. This lady had only very few words and so was unable to communicate verbally.

The staff member suddenly said that she thought the lady was in pain. She had noticed a movement. This movement was tiny; the lady slightly moved her thigh. She had indeed slipped down the chair. The staff member said she had noticed this movement before and she thought that it indicated backache. Whether it did or not could not be said for certain but it did show how observant the staff member was and how she was able to use that observation to make sense of what might be happening to the lady.

Staff role in informing and advising GPs

As evidenced elsewhere in this report (cf. Chapter 6) direct care staff were seen by general practitioners (GPs) to play a vital role in the pain assessment process. Their knowledge and experience of the person were seen as critical. Indeed a number of GPs commented that, without the staff input, they would be at a significant disadvantage in making a diagnosis:

So I think I've put a lot of emphasis on the day-to-day carer's assessment because the patients will only come to see the GP once every six months and yet the carers are working and living with them on a daily basis. They

see subtle changes and how they are reacting to their environment and interacting with other residents. If there were significant pain there then those would be the things to be picked up on.

(GP)

The staff were clearly pleased when the doctors valued their knowledge and insights but they also recognised that sometimes they were asked to take too much responsibility. Few of the direct care staff in all of the settings had any medical training. The fact is that many of the staff are employed precisely because they do not have a medical background. The moves and changes put into place with the implementation of normalisation, inclusion and person-centred planning mean that organisations have sought to employ staff who take a more social disability approach and so medical support and advice comes, as with all citizens, from medical services (O'Brien and Lovett, 1993). Changes in the needs of the people being supported, often brought about by the ageing process, mean that staff are now sometimes being asked to make judgements that they are not trained to make:

We called the doctor once when one of the ladies was ill. I phoned at 9.00 and he said he would do a home visit. I phoned again at 3.00 and he said 'do you think she should be in hospital?' Well at 4.00 they phoned me back and said again did I think she should be in hospital and I said I think so. The ambulance came and she died at 5 o'clock ... I did not recognise a stroke.

(Staff)

There is a need for the development of simple protocols that can help staff to make decisions about seeking medical intervention. There is an organisational responsibility for the provision of a pathway that states how long staff should wait before recontacting a doctor after the initial request has been made. This would give staff clear instructions and so enable them to make demands without feeling that they are being over-demanding. Without this support, staff sometimes feel that they should not worry the doctor and so try other sources for advice and support.

There were a number of references made by staff to researchers where they described contacting their friends or relatives who they thought might have some advice on medical issues. The following is an example of this.

Peter: case study 5

Peter had a recurring abscess. The staff commented that they were unable to know when he had it until 'You could see it on his face' or 'It was all swollen up'. The swelling went down and the dentist said it was all right. It then appeared again. This was also at the same time as Peter was 'Taking an awful long time to eat his food'.

A locum GP visited and said that he was all right, there was nothing wrong. A few days later one of the staff called a relative who was a physiotherapist. She explained to the physiotherapist that Peter was not well and had 'a terrible cough', and that she also thought he had an abscess and she did not know what to do. The relative said that it sounded as though the infection had gone to his lungs.

The staff member phoned the doctor and demanded a visit. The man was immediately taken into hospital with a lung infection.

Lack of assessment tools or process

There was only one example of a pain assessment tool and monitoring process being used by support staff interviewed. This involved the use of a FACES scale (Wong *et al.*, 2001). The support staff described using this tool as part of the administration and review process to assess the effectiveness of analgesia:

We've made a little smiley face that we offer, it's a smiley face that progresses to one that cries. So they can point and say how they feel. So then you go back after you've given the pain medication and ask how they're feeling and hopefully they're back up to the smiley face.
(Manager)

This type of tool does require a level of understanding about the purpose and meaning of the faces shown. The person needs to be able to understand that the face is representing a pain experience and they also need to understand that they are being asked to relate this to themselves.

In all other sites, when support staff were asked about pain assessment tools, they stated that they did not use one. This is despite the fact that there are a number of tools that have been developed to assess pain and distress in people with a learning difficulty who have communication difficulties (see, for example, Regnard *et al.*, 2003). In one site, the CLDT psychologist identified a useful pain assessment tool,

which they had provided to the managers of the support staff. However, when interviewed, the support staff were not aware of this tool. Support staff in a number of sites commented on the pressures of work and the lack of time to fill out assessment tools, although many stated that they would be useful if they were quick and easy to complete.

In the context of people with a learning difficulty and dementia, it is important to use a pain assessment tool that addresses non-verbal indicators of pain and the history of the expression of pain in the individual. The American Geriatrics Society has identified that six areas should be addressed in any pain assessment tool for people with dementia who have impaired communication. These areas are:

- 1 facial expression
- 2 verbalisation
- 3 body movement
- 4 changes in interpersonal interaction
- 5 changes in activity patterns or routines
- 6 mental status changes (American Geriatrics Society, 2002).

It is important to note that support staff did pick up on many of these areas, as evidenced within this chapter. Nevertheless, these were not carried out systematically. It is critical, as part of the assessment process, that support staff capture and record important information to support the judgement of a clinician. They are best placed to record the subtle changes that may indicate pain (Regnard *et al.*, 2003).

The administration of pain relief

The administration of pain relief was an area in which staff played a critical role. They often had to make decisions about pain relief, which they sometimes felt ill-equipped to make. Indeed, sometimes they felt that they were being placed in an unacceptable position, which was seen to be inappropriate, and indeed not good medical practice:

We were told that we could give her a maximum of eight codeine tablets a day, but to find a balance, this is from the GP to us, find a balance. So we devised a method ... she was still distressed ... in the end we got in the community nurse and said 'we are not prepared to do this any more, these are medical decisions that you are asking us to make, it's not fair'.
(Manager)

This sentiment was picked up by one GP who commented:

These [care staff] are people with little or no medical training and I think for you to say 'well it's your responsibility to decide when to give pain relief', that's asking a lot of them really.
(GP)

Very often pain relief is prescribed 'as required' (PRN). The problem arises when someone has dementia. As discussed earlier, people with dementia will have great difficulty indicating that they are in pain. They may lack the necessary verbal skills; they will lack the sense of the geography of their body and so not be able to indicate where the pain is; they will also have memory impairment, which will make them less able to make sense of the sensation of pain.

How then does the person caring for the person with dementia decide that they are in pain?

The possibility of misinterpreting the behaviour of people with dementia who are in pain was recognised by staff who commented:

I mean she could not say she was in pain, she would just lash out at you.
(Staff)

Such behaviour, seen as 'challenging', can lead to the inappropriate use of sedation or antipsychotic medication (Elenchenny and Shah, 2001; Balfour and O'Rourke, 2003). Staff have undoubtedly a critical role to play in determining what medication is given. If they describe the lashing out as 'challenging' then it is probable that there will be a response that focuses on behavioural management or even the use of sedation or anti psychotic medication. If they describe it as 'pain behaviour' then hopefully the response would be to give both pharmacological and/or non-pharmacological pain management.

Staff role in making decisions about when to give pain relief was highlighted within this study and reflected the experiences of staff working with people with dementia in

the general population. There is evidence within the general population that, even when analgesia is prescribed, this is not necessarily administered appropriately. Indeed, within the general population of people with dementia, there is less prescribing of analgesia than among age-matched people without dementia (Horgas and Tsai, 1998) and, even when analgesia is prescribed to a person with dementia, 83 per cent of them did not receive their medication (Dawson, 1998).

Because of this the prescribing of pain relief 'as required' (PRN) to people with dementia is not recommended (SIGN, 1998).

Many examples have been given above of when staff seemed to pick up on people's pain. What they were not able to demonstrate was what proportion of pain needs were not being picked up and were not adequately managed. This is the nub of the problem with PRN prescribing for pain relief. Nevertheless, staff did see it as part of their role to make decisions 'as required' about the administration of pain relief. An example of this follows.

Jane: case study 6

Every morning Jane screamed, shouted abuse and hit out as staff helped her out of bed and along to the bathroom. There was some feeling that this behaviour was because she did not want to get out of bed and face the day. In fact she was seen as 'being stubborn'. This seemed to be confirmed by the fact that the screaming and hitting stopped after the bathing was done and as the day progressed.

The morning procedure became increasingly distressful for everyone concerned.

Jane had arthritis.

This is a painful condition, which is worse in the mornings after the person stiffens up during the night.

A decision was made to give Jane paracetamol 20 minutes before she got out of bed.

This resulted in a complete change in her behaviour. She was clearly no longer in pain and went happily to the bathroom.

Non-pharmacological interventions to relieve pain

There was, throughout the study, evidence of staff using non-drug forms of pain relief. These were sometimes used as a means of relieving pain and sometimes as a way of reducing the possibility of the pain occurring. The following interventions were noted but they are not exhaustive and are not presented in an evaluative or prioritised form. They are simply given as examples of interventions used. Staff comments on their effectiveness are included.

It is important to note, however, that, for chronic musculoskeletal pain, the ‘application of heat and massage or positioning can sometimes be all that is needed’ (McClellan, 2003, p. 482). This type of pain is associated with increased age and therefore one to which the people in this study were susceptible. Chronic degenerative joint disease causes pain in the back and limbs, and osteoporotic spinal deformity causes back pain (see comments from people with dementia in Chapter 3 to illustrate this). It is in this context that the following seems to be a valuable contribution.

■ Aromatherapy oil and massage:

You can see a difference in her, very much, very relaxed and she will sleep afterwards ... well into the evening even if she had it at lunchtime. You can see the change. She is quite cranky [with pain] beforehand.
(Staff)

We have a lady who comes in and does aromatherapy. After she has done it with Keith he can move his arms and legs [which had been stiff] and that lasts for a night, probably a day.
(Staff)

She also does it with Pam, she does Reiki with her and afterwards she is very chilled, very relaxed, maybe it takes the pain away from her arthritis, I wouldn't know but she is very chilled and relaxed.
(Staff)

■ A massage mattress:

She has a mattress with a massage sensation in the bed. If we put that on in the morning before she gets up that really helps reduce the pain.
(Staff)

■ Use music that the person likes:

Even when she is in pain if you can get her to sing that relaxes her. Her rendering of Delilah is something.

(Staff)

■ Whirlpool, bubbles, peace and quiet, warm bath:

We get her into the [whirlpool bath] warm water, the bubbles, peace and quiet and ... by and large she is different person ... and, you know, you say 'are you ok, do you want to stay for a while?' You know, you get a response, I mean we were told by speech and language therapist that she could not communicate on a basic level, well we manage it.

(Staff)

Well I think once she has had a bath she's ok, she's comfortable.

(Staff)

■ Sitting with the person, calmly asking about the pain:

I find that, even sitting down and saying 'are you in pain?', if you have a problem you can tell me', that seems to take the pressure off and calm her down a bit.

(Staff)

■ Being slow and relaxed when moving people:

She was quite rigid in the mornings so, when getting her out of bed and giving her personal care, it was nice and relaxed, no big rush.

(Staff)

■ Pressure sore cushion:

Well we use the pressure sore chair cushion and we have a routine where we change her position every two hours.

(Staff)

■ Special comfort chairs:

It's a [name of adapted specialist] chair. It reclines back as well, so it moves posture, which relieves the pressure from one area to another. It has pressure-relieving elements in the chair itself and then on top of that

you have a pressure-relieving cushion, which again you can move around.

(Staff)

■ 'Lovely things at night':

He has poor circulation and his legs and feet are always cold. We have a double duvet that comes right over so it doesn't slip off, and then a blanket that is folded four times to go over his feet, it is a pocket to put his feet into and then he has another lovely big blanket on top so he can pull that round his shoulders, we always leave the heat on at night as well ... I don't know what else we can do.

(Staff)

The significance of almost all these interventions is that they are directly or indirectly relaxing. People in pain will tense up and stiffen their body. Many of the above interventions were ways of relaxing the person. This did not necessarily take the pain away but it made the secondary impact less and so made it more tolerable.

The use of some of these at night, especially aromatherapy, would help people to sleep better. The example given of how long someone slept after being given aromatherapy would indicate that this approach would be particularly beneficial at night-time.

The use of individually adapted chairs is important to highlight. These may well serve to reduce the occurrence of pain as well as give support and comfort to parts of the body that are painful. It is important to emphasise that these chairs are made for individuals and must be reconstructed before being used by others. The physiotherapist is the person to refer to for advice.

A number of these interventions involved touch. Although no one mentioned touch directly this was clearly a significant component in the therapy. People with dementia need touching, both as a form of communication and as a source of comfort (Goldsmith, 1996). People in pain are, as evidenced above, relieved of pain or at least enabled to cope with it through the appropriate use of touch. There is, however, an anxiety among staff about touching people:

Well with our abuse policy ... you would never unnecessarily touch people, in our care ... I mean for years I've been giving goodnight kisses and hugs because nobody does it do they, I mean would you want to live your life without a cuddle, I wouldn't.

(Staff)

This is a cause for concern. There are good reasons to be cautious about the use of touch. The history of the service shows that touch has been and indeed is used sometimes inappropriately. Unfortunately, there is a danger that 'not touching' is now also used inappropriately.

Summary

It was evident that staff needed to increase their awareness that pain is an issue for people with a learning difficulty and dementia. Staff have a critical role to play in recognising pain. Their relationships and involvement with the individual mean that they are best placed to observe changes in behaviours. It is these changes that they need to be able to describe and illustrate in order to inform the clinician's assessment. There was a clear need for support staff to be more systematic in their recording of pain, as this information was important to pain assessment. Support staff are involved in the administration of medication. This can place them in a difficult position when they are expected to make decisions about 'as required' analgesia. Support staff demonstrated a number of non-pharmacological interventions that were effective in aiding pain relief.

Recommendations arising from this chapter

- 1 Support staff must receive training about the pain needs of people with a learning difficulty and dementia.
- 2 There needs to be a simple, agreed system of recording important information about the individual's pain and its management. This must be used by all staff.
- 3 Support staff need to develop ongoing relationship with identified GPs who demonstrate an understanding of the needs of people with a learning difficulty and dementia.
- 4 Organisations must develop clear and simple protocols that provide instructions and guidance for staff to follow when contacting GPs and other doctors.
- 5 The use of analgesia to manage pain should follow established guidelines (SIGN, 1998; NICE Guidelines, 2004) – this would call into question the current prevalence of 'as required' (PRN) prescription. 'As required' (PRN) analgesia should not be the primary approach to pain management in people with a

learning difficulty and dementia. Analgesic prescription must follow the WHO Guidelines (1996) on prescribing. These recommend regular administration and also that treatment should be adjusted from one step to the next according to increasing or decreasing pain severity, history of analgesic response and side-effect profile.

- 6 The use of non-pharmacological interventions for pain management should always be considered.

Overall recommendations are listed in the Appendix.

6 General practitioners: their role, involvement and perspective

Despite the fact that ‘general practitioners are the health professionals most commonly consulted by people with intellectual disability’ (Lennox and Eastgate, 2004, p. 601), most medical practices will have only a limited experience of people with a learning difficulty, as they comprise only a small proportion of any GP’s list (NHS Health Scotland, 2004). A study carried out in Glasgow found that, on average, each GP would have only five people with a learning difficulty registered with them (Glasgow UAP, 2002).

It is also usual that most GPs will have limited experience of people with dementia even within the general population. ‘A GP with 1,500 to 2,000 patients can expect to include 12 to 20 people with dementia, depending on the age profile of the list’ (Alzheimer’s Disease Society, 1995, p. 2). The amount of experience that any one GP will have, therefore, of people with a learning difficulty who also have dementia is going to be fairly limited.

This clearly puts the average GP at a great disadvantage when presented with someone with a learning difficulty who also has dementia. *Valuing People* (the government strategy for people with a learning difficulty in England and Wales) highlights this problem by commenting that:

... the health needs of people with a learning disability may not be recognized by doctors ... with no experience of working with people who have communication difficulties.
(Department of Health, 2001, p. 59)

This study found highly varied experience, knowledge, skills and attitude among GPs in relation to the issue of learning difficulty and dementia. Clearly, this also led to significant variations in knowledge, skills and attitudes towards the pain management needs of this group.

Lennox and Eastgate (2004) reinforce the idea of the importance of people with a learning difficulty having one doctor who consistently meets their health care needs. This is discussed further below. It is perhaps important to note that, while this arrangement undoubtedly will have advantages for the patient, it will also accrue benefits for the doctor. It will have the effect of countering the effects of low numbers

by increasing the GP's experience of, knowledge of and skills in working with people with a learning difficulty and in particular people with a learning difficulty who have dementia.

This chapter will look at the impact of the doctor's experience, knowledge, skills and attitude on the pain care needs of people with a learning difficulty who also have dementia. This will be evidenced using the perspectives of support staff and members of community learning disability teams (CLDTs), and those of the six general practitioners interviewed.

General practitioners: the views and experiences of staff

The key issues that emerged from the interviews were:

- 1 a wide variation in the working relationship with and practices of doctors
- 2 unacceptable practices
- 3 good practice.

A wide variation in the working relationship with and practices of doctors

Support staff reported a wide variation in the practice, knowledge, skills and attitudes of the various general practitioners they had encountered in relation to the people they supported. These variations were both within individual medical practices as well as across geographical areas. These variations meant that often staff members were discriminating about the doctor they approached. Sometimes, this resulted in them making decisions to delay seeking an appointment until they could see a particular GP.

Valuing People (Department of Health, 2001), quoting from *'Facing the Facts'* (Department of Health, 1999), underlines the inconsistencies in health care provision for people with a learning difficulty in different parts of the country. Certainly, there was evidence from staff of a wide variety of responses from doctors. What was interesting was that these responses were not linked to the economic situation or the geography of the practice. The variations existed across the rural/urban and richer/poorer divides.

Unacceptable practices

Support staff reported examples of practices that were unacceptable and certainly were not conducive to the development of good relationships. There was a clear lack of respect for the person with dementia and poor communication skills, which hindered or even blocked the acquisition of good information on which to determine an accurate diagnosis of pain. The need to physically examine the person was often omitted. This despite the fact that 'It is easy to miss something in a patient who has problems communicating' and so the doctor should 'Always fully examine the patient' (Lennox and Eastgate, 2004, p. 603).

Diane: case study 7

Diane had been having some ongoing problems with abdominal discomfort. An appointment was made for her to see the GP at a time her key worker was on shift. The manager of the home and the community nurse also arranged to attend the appointment.

After arriving at the GP's surgery the manager went up to the reception desk and was told that the GP was ready to see Diane. Diane, her key worker and the manager made their way through to the consulting room, where the GP and community nurse were waiting.

As they were entering the room the GP waved her hand in a dismissive gesture and told the key worker to leave taking Diane with her:

She just used hand gestures to tell us to leave. So we walked out and the manager and the community nurse stayed. We are the people who know her, her moods, behaviour, knew why we were there and we got sent out. I've never gone to that GP again.
(Staff)

At no point did the GP speak directly to Diane or examine her physically.

We do refer to our GP colleagues, there is a hesitance or reluctance to actually physically examine the person and that could be a fear factor, it could be, I mean some GPs are better than others but there are some GPs coming out they have a tendency to stand back and look at the person from a distance as opposed to really getting in there and carrying out proper examinations.
(Community nurse)

General practitioners

He [GP] obviously found people with a learning disability difficult and so to have a learning disability and dementia was a double whammy.
(Member of CLDT)

People with a learning difficulty can often present particular challenges to others who are not used to communicating with them, and indeed staff who do not routinely work with and support people with a learning difficulty can often be fearful of the person and are not willing or able to engage (Department of Health, 2003; Wilkinson *et al.*, 2004). They may also recognise their own lack of knowledge and skills, and this may lead to interactions that are tense, inadequate and even, sometimes, rude.

The need for GPs to develop specialist skills was evident. One GP, however, explained one obstacle to achieving this: given the pressures of time on GPs they would need an incentive to specialise and give extra time to people with a learning difficulty:

To specialise in something like that [learning difficulty] or go on courses ... there needs to be an incentive.
(GP)

Good practice

The research did, however, reveal exemplary practice among many of the practitioners involved with the sites studied. It was evident throughout that support staff were discriminating in trying to access 'good' doctors. Support staff were also clear about the doctors who they trusted and with whom they had respectful and confident relationships.

From the staff perspective there were some core attributes that they sought in a 'good' GP. These included a GP who would give time to understand the needs of the person with a learning difficulty and dementia, and who would specifically attend to their pain needs.

The staff were clear that the nature of the interaction between the person with a learning difficulty and dementia and the GP was critical. Where the doctor acknowledged, spoke to and listened to the person with a learning difficulty, this was recognised as fundamental not only to facilitate the assessment process but also to enable the person with a learning difficulty to cope with the medical intervention:

Well first of all he'll [GP] come in and he'll sit down and talk to the person.
(Support staff)

She wants to know everything, she approaches it [the consultation] very low key and tells 'Roger' exactly what is going on.
(Staff)

The development of the relationship over time between the GP and the person with a learning difficulty was also seen as critical to the GP being able to communicate with and understand the person with dementia:

The doctor has gone through the mill of all the ups and downs through the years.
(Staff)

We have had locums coming up. You can tell the difference, not the relationship there.
(Staff)

Another critical factor was the GP's willingness to listen to the staff. The staff recognised that they often had essential breadth and depth in their knowledge of the person. They would often pick up subtle changes and signs that would not be evident during a short consultation. It was important that doctors listened to them and took their concerns seriously. Lennox and Eastgate (2004) reinforce this finding when they state:

... improvement in their [people with a learning difficulty] health care can be made through a variety of strategies. These include maximizing communication and cooperation with all those involved and ensuring adequate information from support staff.
(Lennox and Eastgate, 2004, p. 601)

He will listen to staff and he will book double appointments, the last one we had we were with him for 20 minutes, he does listen.
(Staff)

It is, of course, difficult for general practitioners to be both knowledgeable and experienced in all areas of medicine. What was apparent in this study was that, where general practitioners for a variety of reasons had taken a special interest and developed specialist knowledge about people with a learning difficulty, staff reported that the service was sensitive and responsive to the needs of people with a learning difficulty.

Views and practice issues as reported by general practitioners

The GPs interviewed were recommended by the staff group, so are perhaps atypical and do not necessarily represent the experiences and practices of other doctors. During the interviews each GP occasionally represented the views of other members of their practice, but generally they gave personal reflections and were able to reference specific examples from their own practice.

The key issues that emerged from the interviews were:

- 1 the decision to specialise
- 2 the importance placed on staff observation
- 3 diagnostic overshadowing
- 4 the lack of any formal assessment tool.

The decision to specialise

Though not all GPs interviewed had chosen to specialise, these GPs, simply through exposure to people with a learning difficulty, had developed their knowledge and skills in this area. A number of the GPs, however, stressed that they had made a conscious decision to develop their own practice and involvement with people with a learning difficulty, and to build on this as an area of some expertise. They cited a number of reasons for this including, in two of the practices, the closure of a local long-stay hospital. The development of a relationship with a local provider of services to people with a learning difficulty led to a growth in interest in the other doctors. The personal experience of a close relative with a learning difficulty prompted another doctor to take on this area of work.

Whatever the reason, what was clear was that this had led to a commitment and involvement, which made the support for people with a learning difficulty and an attention to their pain needs a higher priority:

We took a positive decision to take on as many people as asked us [from the local long-stay hospital when it closed] within our practice zone ... I found it interesting and challenging.
(GP)

We have had all the people with a learning disability registered with me.
(GP)

My experience of trying to help patients with a learning disability is often that they find exposure to health services quite frightening and that they feel less frightened and more comfortable if they can see one person, one doctor or somebody who they can feel comfortable with and who they know is not going to either disregard what they say or not take account of their particular views.
(GP)

There was recognition, however, that this might cause some problems when the doctor was not available and others had to take over:

If I'm on leave they come and see other doctors who haven't seen them before; it can be much more difficult to assess them.
(GP)

The GPs also recognised the importance of the relationship that they developed over time with the staff and patient:

I think that they know that they can always phone me up. I am always accessible. I think the fact that I have had a personal relationship for longer is important.
(GP)

I think that you need to trust the staff; you need a good ongoing relationship with them.
(GP)

This striking of a balance between the need to provide continuity within relationships based on trust and the realities of GPs' work life is reinforced by Lennox and Eastgate (2004) who observe that it is important for people with a learning difficulty to:

Develop a relationship with one general practitioner, and to see that GP at each consultation if possible. Comprehensive records should be available to other GPs in the practice for when his regular GP is unavailable.

(Lennox and Eastgate, 2004, p. 603)

The importance of staff observation

Across all the case study localities it was constantly and consistently reported by GPs that they relied heavily on staff observations as a key aspect of their assessment for pain. The GPs were clear that it was the staff who knew the person best. The staff knew the baseline behaviours of the people they supported. They were in constant and intimate contact with the person with dementia and so were well placed to pick up on even subtle behavioural changes:

I think I rely almost totally on the observations of people who know the patient well.

(GP)

If I go in and interview them [people with learning difficulties and dementia] for ten minutes it's extremely difficult to pick out how bad the pain is and how frequent it is and where it is so it is always the carer or the nurse or the assistants who would tell me whether there was a change in their behaviour.

(GP)

I would take more notice of the views of experienced staff ... than I would probably from my own observations.

(GP)

Of course, this required that they had a good relationship with the staff. They felt that they could trust the staff's judgement and they made time to listen to the staff. However, this was totally dependent on the quality of staff. Some GPs observed that, in certain settings, support staff did not facilitate the assessment process. A high staff turnover, the use of agency/bank staff and lack of training called their observations into question:

[Support staff were] not very well established, they're working in shifts and they pass on information from one to the other and it gets mixed up and you get calls to go and see people and it's not really clear and nobody really knows what's happening and their observations in those situations are not particularly useful.

(GP)

Seeing beyond the dementia

Diagnostic overshadowing is a tendency that is apparent within the general population in relation to dementia. It is also a tendency in relation to people with a learning difficulty (Mason and Scior, 2004). Often issues that are related to the fact that someone has a learning difficulty 'override and obscure physical illness' (Ng and Li, 2003, p. 12). This means that, once someone has been diagnosed with a learning difficulty and/or with dementia, that particular diagnosis often overshadows other considerations and conditions.

There was evidence that, for people who have a learning difficulty and dementia, there might be a tendency towards diagnostic overshadowing. This meant that physical changes were not always given priority. In this way pain can get moved down or off the agenda, or will maybe never get on it:

I think that there is a tendency just to focus on his mental state, his dementia, his Parkinson's and perhaps forgetting some of the other physical things.
(GP)

Just taking part in this interview has flagged it up [the need to consider pain as an explanation for changed behaviour] into our attention again.
(GP)

The assessment processes and prescribing

None of the GPs interviewed in this study used any formal assessment tools. However, they did describe the use of assessment processes to establish if pain was present. There are a number of tools used to identify pain in people with dementia. In the context of people with a learning difficulty and dementia it is important to use a pain assessment tool that addresses non-verbal indicators of pain and the history of the expression of pain in the individual. (See, for example, the tool developed by the American Geriatrics Society [2002] with its six areas that should be addressed in any pain assessment tool for people with dementia who have impaired communication.)

As highlighted in Chapter 5, the issue of the use of 'as required' analgesia (PRN) was of concern. All but one GP prescribed analgesia 'as required', which is not in keeping with the current guidelines on pain management (SIGN, 1998; NICE Guidelines, 2004).

Summary

Despite the fact that 'general practitioners are the health professionals most commonly consulted by people with intellectual disability' (Lennox and Eastgate, 2004, p. 601), most GPs have little contact with people with a learning difficulty. They have even less contact with people with a learning difficulty who also have dementia. This means that they have little knowledge or experience to draw on when presented with someone with a learning difficulty and dementia. This will, of course, have an impact on their knowledge and skills in relation to pain management in this group. This study did find that some GPs had, for a variety of reasons, developed a special interest and involvement with people with a learning difficulty. Where GPs had chosen to specialise, they reported an increased awareness and knowledge. They also described the work as both challenging and rewarding.

Staff reported a variety of practices among GPs. These ranged from the unacceptable to the exemplary. Staff were, as a consequence, discriminating in the GPs that they used.

GPs were clear that, even where they had chosen to specialise, their knowledge of the individual was sparse compared with the knowledge of direct care staff. The GPs were, therefore, dependent on staff for critical information as part of their assessment. This was particularly problematic where staff were not familiar with the person with dementia. A high staff turnover, the use of agency/bank staff and lack of training called their observations into question.

There was also recognition among a few GPs that there may be some diagnostic overshadowing. This meant that, once the dementia had been diagnosed, other physical ailments tended to be given less prominence and there was the risk that pain was not recognised.

None of the GP's interviewed used any particular assessment tool.

Recommendations arising from this chapter

- 1 Learning difficulty studies need to be included in undergraduate and post-qualifying education for GPs.
- 2 There should be encouragement for some GPs to specialise in both learning difficulty and dementia.

- 3 There is a need to develop the use of an assessment tool that would facilitate the assessment and diagnosis of pain.

Overall recommendations are listed in the Appendix.

7 The community learning disability team: their role, knowledge, experience and views

The community learning disability team (CLDT) or community team, learning disability (CTLTD) describes the group of people, from various disciplines, who provide specialist health care and advice for people with a learning difficulty. The acronym CLDT will be used throughout this chapter.

Members of the CLDT have a vital role to play in meeting the health needs of people with a learning difficulty. This role is recognised and expanded within the recommendations of *Valuing People* (Department of Health, 2001), and where the establishment of 'health facilitators' is also described as follows:

Their task will be to facilitate, to advocate and to ensure that people with learning disabilities gain full access to the health care they need ... the health facilitator role will be vital in helping people with learning disabilities navigate their way around the health service.
(Department of Health, 2001, p. 64, s. 6.13)

The CLDT members and, in particular, the community learning disability nurse, were identified as being well placed to take on this health facilitation role. This means that they have a current and ongoing significant role to undertake in pain identification and management. This study, therefore, sought to identify how this role was presently being carried out and to make recommendations that would enhance their role in pain recognition and management.

The following themes emerged throughout the study:

- 1 differences in team composition and accessibility
- 2 the role of CLDT members in pain assessment and management
- 3 the focus on younger people
- 4 the need to raise awareness of pain in older people with a learning difficulty
- 5 the need for multidisciplinary working
- 6 the need for effective recording procedures.

Differences in team composition and accessibility

There were, across the study sites, considerable variations in the composition of what is defined as a CLDT. There were also variations in staff understanding of the different roles and responsibilities undertaken by members of the CLDT. In one site the support staff were initially unable to identify the members of the CLDT and were not aware of their role in pain management. It is important, also, to note that there was reference to the difficulties of getting hold of members of CLDTs because of the pressures of work:

The problem with community learning disability teams is they are so short staffed that it is very difficult to get hold of them ... so you tend to go there for something urgent or kind of individual as that [thinking someone was in pain]. We go straight to the GP.

(Staff)

These variations and pressures had a demonstrable impact on the identification, treatment and management of people's pain.

The role of CLDT members in pain assessment and management

There was evidence throughout this study that, in the context of the population of people with a learning difficulty, members of the CLDT had a significant role:

I find them [people with a learning difficulty] quite a difficult group and I think general practice isn't ideally geared to cater for them, I think that's where really the CLDT has a major role to play and the GP slightly more in the background.

(GP)

Members of the CLDT further identified their role in pain recognition and management. This was particularly true of the community learning disability nurses.

Numerous examples were given of how pain is integrated within the core assessment process. The use of assessment tools, which highlighted individual ways of expressing pain were described. These were usually part of the general health check. They consisted of a number of tick boxes, which would identify how the person with a learning difficulty expressed pain. This then formed a baseline for future assessment.

People with a learning difficulty and dementia would be referred because of a change in their behaviour. CLDT members were aware of the need to look beyond the presenting behaviour and indeed to consider the possibility of pain as an underlying cause:

We would rule out any medical issues that may lead to pain prior to any behavioural, I mean with our sort of services the behaviour team would only get involved as a last resort, when everything else had been considered, both physical and mental health was considered first.

(Community nurse)

We always look for a reason, because it's easier to deal with the reason than it is to deal with the challenging behaviour and take the reason away.

(Community nurse)

The focus on younger people

There was a contradictory theme that ran through the interviews. Despite the evidence that staff were acutely aware that pain was an issue for people with a learning difficulty, this did not seem to translate to the context of older people with a learning difficulty and therefore people with dementia.

Indeed the findings described elsewhere in this report indicate that pain in people with a learning difficulty and dementia was often not being recognised or even considered. This would suggest that pain was not always placed so obviously high on the agenda when assessments were being done of people with dementia.

The following are recognition of this:

Most people that I work with don't think routinely about giving pain relief [to older people with a learning difficulty] ... whereas I know a lot of elderly people [in the general population] routinely take pain relief to cope with aches and pains.

(Community nurse)

But until I had the conversation with you [the researcher] I didn't think that he might be in pain, I just saw the dementia.

(Community nurse)

The need to raise awareness of pain in older people with a learning difficulty

There was evidence throughout that members of the CLDTs had pain as part of their general assessment process. Although pain was sometimes considered in relation to people with dementia, it was not given priority as an explanation when applied to older people and people with dementia. Possible explanations for this were discussed in Chapter 3.

The need to raise the level of awareness about the possibility that people with dementia might be exhibiting behaviours that were the result of pain experiences was underlined by the impact on staff knowledge and awareness as a result of taking part in this study.

It was noteworthy that, in many of the sites, involvement with the research team resulted in CLDT members considering, discussing and sometimes identifying the possibility that there might be greater pain among the people they supported than had previously been acknowledged. In a number of sites people had actually been identified as being in pain when this had not been considered or diagnosed prior to the research involvement:

Since receiving the leaflet about the pain study two of the people with a learning disability and dementia who had challenging behaviour we treated for pain and their behaviour has significantly changed for the better. We did not think that it might have been pain, I feel really bad that we didn't think about pain first.

(Community nurse)

Some of the individuals we work with ... we would look at physical issues relating to deterioration and pain is not one that has come up on the assessment, it's perhaps something we need to look at.

(Community nurse)

The need for multidisciplinary working

The importance of the role of CLDT members in pain recognition and management has been acknowledged above. There was, however, a concern that, despite the recognition of pain as an issue, many people were not getting their pain needs met. It was hard to work out what the reasons might be. This may be, as stated earlier,

that older age and dementia are obscuring the individual's needs. A further contributory factor may well be the level of communication between the various people involved in the support of people with a learning difficulty and dementia.

Another possibility is that, in fact, members of the CLDT do not have as much access to people as they might need in order to be involved in pain diagnosis. This may well be the consequence of the pressures placed on CLDT members and that support staff are not referring people because they are not themselves considering pain as a possibility. Evidence elsewhere in this report suggests that staff are more likely to see the pain behaviour as 'challenging' than as a form of response to pain. It may be that the support staff are more inclined to see a non-medical issue as an explanation of the behaviour. This will, of course, impact on the type of referral they make and to whom the referral is made:

But in a way that's one of the things about the learning disability service is that it tends to concentrate often on behavioural issues and misses out on this bit here [pain], which is one of the things that we're trying to change.

(Psychologist)

Another dynamic might be the different training, education and perspectives of the various people involved. There were a few examples of CLDT members identifying difficulties around the acknowledgement of health needs. This was seen to be the consequence of the different perspectives of support staff and medical staff. The following quotes from a number of CLDT members highlight an issue they considered relevant:

I think, quite noticeably, the staff are in social care and I think health is quite low on the agenda.

(Occupational therapist)

Sometimes it is hard to maintain a relationship ... They will say 'oh it's just attention seeking' or 'oh he's just jealous' or 'she's always been like this' and you ask for some concrete explanation for their hypothesis ... and people, sort of glaze over.

(Psychiatrist)

As highlighted elsewhere in this report, staff who support people with a learning difficulty are generally not medically trained. They often feel vulnerable in their assessments and look to professionals with a medical training to inform and support them:

We [community nurses] would often assist the staff, if you were monitoring it you could change that list of guidelines of signs and symptoms as you were monitoring the medication effectiveness, if you get staff to record how the person is once they've had their medication to see if that's eased their pain and helped them then you could change that, you could keep reviewing that with the staff, liaise with the GP and change that when necessary.

(Community nurse)

Members of CLDT clearly do this but, in relation to pain among people with dementia, there would appear to be a need for greater dialogue.

The need for effective recording procedures

Within the context of effective pain management (McClellan, 2000), there were a number of examples of ineffective assessment processes. An illustration of this is that all the pain assessment methods described by CLDT members were in the context of a brief checklist around some aspects of pain assessment and not part of a comprehensive pain methodology (American Geriatrics Society, 2002). This will result in some people with a learning difficulty and dementia being left in pain. This will be exacerbated by the lack of specialist pain assessment tools being used and the use of explicit pain management pathways highlighted within this study.

If there had been an effective recording process about pain in place then support staff would have been able to draw from this a clear picture of the pain experience and response of the person. Clear and effective communication between all the various people involved in supporting the person with dementia is essential. While this is an obvious statement to make, it is critical that it be acted on if people with a learning difficulty and dementia are going to get an equitable service.

Summary

There was a noted variation in the structure and composition of CLDTs across the UK. These variations had implications for the focus and practice of CLDT staff. It clearly had implication for the amount of time and attention given to the issue of pain in older people with a learning difficulty and dementia. These variations may have implications for the role of 'health facilitators', which was envisaged by *Valuing People* (Department of Health, 2003).

There was evidence throughout that members of the CLDT, particularly community learning disability nurses, saw assessment for pain as part of their role. This was described as an integral part of their training.

Despite being aware of and focusing on pain in younger people, they did not appear to give the same priority in the context of older people with dementia.

The process of taking part in this study heightened CLDT staff awareness of pain issues in older age and in people with dementia, thereby suggesting that this issue can be relatively easily integrated into staff practice.

The importance of multidisciplinary communication and assessment was recognised, but there appeared to be some obstacles to this being implemented sufficiently to make certain that all pertinent views and perspectives were taken into account.

There were examples of pain assessment procedures, but limited evidence of these being used effectively across disciplines. The use of dedicated pain assessment tools for people with a learning difficulty and dementia was not found. A number of respondents recognised the need to maintain good written accounts of behaviours and responses to pain relief. Indeed, some expressed a need for more rigour in producing written evidence of pain assessment and management.

Recommendations arising from this chapter

- 1 Members of the CLDT must have a more heightened awareness of the impact of age and dementia on people with a learning difficulty.
- 2 All staff should receive training on the impact of older age and dementia on people with a learning difficulty.
- 3 Pain in older people with a learning difficulty and dementia should be given higher priority as part of the assessment process carried out by members of CLDTs.
- 4 There is a need to develop simple but effective assessment tools, which can be used in a multidisciplinary context.
- 5 CLDT members and support staff need to develop regular reviews of older people with a learning difficulty and dementia who are possibly experiencing painful conditions.

Overall recommendations are listed in the Appendix.

8 Common painful conditions experienced by older people with a learning difficulty

This study demonstrated that all types of staff were increasingly involved with the pain experiences of older people with a learning disability and dementia. It was evident, however, that many people were not aware of the types and range of conditions that may be experienced by older people with a learning difficulty. This chapter will look at the conditions that were most commonly encountered. It addresses only conditions highlighted during the research and does not set out to provide an exhaustive list of the conditions of older age. It should be noted, however, that, perhaps not surprisingly, the conditions described are high on the list of common conditions of older age among people with learning difficulty.

The wider context in which these conditions exist will affect the way in which they are recognised, managed and treated. This chapter, therefore, will address the following areas:

- 1 the demographic trends among people with a learning difficulty
- 2 the influence of social policy on practice
- 3 the types of conditions encountered.

The demographic trends among people with a learning difficulty

Increased longevity means that people with a learning difficulty are experiencing the conditions and illnesses of older age (Holland, 2004). People with Down's syndrome will experience these conditions from their early forties onwards and they will have higher incidence of specific disorders than the rest of the general population (Janicki and Dalton, 1998). People with other learning difficulties will have health needs at a similar age to the general population but again will have higher incidence of some conditions (Cooper, 1998). A number of these conditions will cause physical pain.

People will also experience painful conditions that are nothing to do with age but are particular to individuals as a result of their lifestyles, life events and individual health.

Common painful conditions

The onset of dementia is one of the conditions associated with ageing. There is substantial evidence that ageing is associated with high rates of painful conditions, irrespective of cognitive status (Horgas and Tsai, 1998).

As in the general population, the number of people with learning difficulty over the age of 40 years has increased proportionately (Kerr, 1997). Most people who work within the learning disability service have been trained and have been supporting younger people. The need to change thinking and address the fact that the needs of this population are, and will continue to be, those of older age should be given much higher priority.

The influence of social policy on practice

Despite the demographic pressures, ageing in people with a learning difficulty is something that is given relatively low priority in the two learning disability review documents: *The Same as You* (Scottish Executive, 2000) and *Valuing People* (Department of Health, 2003). It is within this context that the findings of this research should be taken.

It is not surprising that some staff in this study reflected the current perspective embodied in social policy and were not sufficiently aware of the changes that older age might bring. In particular they were not as aware of the extent to which people might be susceptible to the conditions that might be painful in older age.

The types of conditions encountered

Musculoskeletal disease

Musculoskeletal disease increases in frequency with age. In one study (Janicki *et al.*, 2002) it was found to be more likely in women and was thought to be attributable to high frequencies of osteoarthritis and osteoporosis. Within the study there was frequent reference to arthritic pain, both from staff and from some of the people with dementia (all of whom were women):

She has arthritis, her joints crack and her knees are swollen. There's a query she has osteoporosis.

(Staff)

I get arthritis in my knees.
(Woman with dementia)

People with Down's syndrome seem to have an increased sensitivity and instability in the neck joint. This is known as atlanto-axial instability as it occurs where the atlas (first vertebra) meets the axis (second vertebra). The vertebrae can slip, causing compression of the spinal cord (Holland and Benton, 2004).

At the back of my neck. There's a wee bone, see the wee bone there.
That's where I get it. That hurts aye.
(Woman with dementia)

Dental problems

Ageing leads to a general deterioration in dental health. People with a learning difficulty are, however, much more susceptible to dental decay and gum disease (Cumella *et al.*, 2000). The impact of poor or consistent dental care earlier in life has a major impact in older age (Naidu *et al.*, 2001). Many people with a learning difficulty have not been able to take adequate care of their teeth. Many had experiences of the dentist, which have made them reluctant to seek further help. The consequence of this has been some distressing dental pain. Some examples of this, which occurred within the study, are given below:

His teeth are quite wobbly and are all on the verge of falling out.
(Staff)

Dental problems that's a big problem because a lot of [older patients] their dental care was not very good over the years when they were in there [long-stay hospital].
(Staff)

She is having problems with her teeth; she has an abscess as well. The abscess keeps reoccurring. It is not until it gets really bad that we notice, because it swells up then. Her appointment is in three months' time.
(Staff)

Impacted ears

People with a learning difficulty are twice as likely to have impacted earwax as the general population (Fransman, 2005). This can cause pain, discomfort, dizziness, noises in the ear and hearing loss. It can also lead to ear infection and, therefore, additional pain. Interestingly, a study carried out by Fransman (2005) found a correlation between the development of earwax and the reduced ability to chew among people who did not have their back (molar) teeth. It is worth considering that people with dementia also have problems with chewing. It may be that this also increases their susceptibility to impacted earwax:

She had wax build-up and discharge. She was agitated, shouting and screaming, she was very unhappy.

(Staff)

She had an ear infection as well and it was only because we noticed it was a bit runny ... and a bit swollen, we phoned the doctor.

(Staff)

Eye infections

People with Down's syndrome are particularly susceptible to dry and infected eyes. Tears are normally formed continually to keep the eye well lubricated and healthy. The naso-lacrimal duct plays a key part in this process as it connects the corner of the eye to the back of the nose. In people with Down's syndrome this tube can be narrowed and easily blocked, causing watery eyes and the risk of infection due to ineffective rinsing (Croft, 2001). Blepharitis is another condition of concern, causing dryness and redness of the eyelid margins and increasing the risk of infection. It has been found to occur in up to 30 per cent of people with Down's Syndrome and about 21 per cent of people with other forms of learning difficulty (Pray and Pray, 2002). It is particularly uncomfortable and irritating during the morning:

Yeah every morning before I give him breakfast, he'll say my head is hurt and in my eyes ... every morning ... he does get sore eyes. They could actually be bleeding a little bit at the corner of his eyes just from hitting his eyes and rubbing them really hard.

(Staff)

He brushes his eyes after he has done his hair, he pokes them with cutlery, he rubs them all the time.

(Staff)

Her eyelid never heals.

(Staff)

She has an ongoing eye infection ... The last time for two months.

(Staff)

Urinary tract infection

Older people with a learning difficulty can experience higher levels of recurrent urinary tract infection than the general population (Janicki and Dalton, 1998). It should be noted that many of the underlying causes of urinary infection are easily treated, for example, urethral stenosis, benign prostate enlargement and bladder stones (Janicki and Dalton, 1998).

The higher incidence of diabetes in people with a learning difficulty, up to 15 per cent (Janicki and Dalton 1998), coupled with the reduced food and fluid intake as a consequence of dementia also leave the person at risk of a urinary infection (Holland, 2004). The discomfort caused by this can be significant:

She had a urine infection. We tried to get a urine sample but we couldn't get one. It took three weeks to get the diagnosis.

(Staff)

I had one client, appeared to be hallucinating, on antipsychotics and had proven urine infections.

(Doctor)

Constipation

The general slowing down of the gastrointestinal system in older age can lead to constipation as well as diarrhoea and irritable bowel syndrome. The pain associated with constipation can be severe and can lead to many behaviours that can easily be misinterpreted and, therefore, mistreated (Lennox and Eastgate, 2004):

Common painful conditions

For the last two or three weeks, she has been rocking a lot, she rocks like that and makes a bit of a noise. I was wondering if she was in a bit of pain. And within an hour we take her to the toilet and she'll have a motion.

(Staff)

She had slept in an upright position for some time. On the fourth day after she came here we discovered that she was quite constipated. We gave her an enema and since then she has slept comfortably back on her pillows.

(Matron)

When someone's purely nursing you can monitor every bowel movement ... when they are in between and they are taking themselves you do not know when they are having their bowels open. It is an even harder problem.

(Matron)

Of course, the susceptibility to become constipated is exacerbated by the fact that people with dementia, unless monitored and supported, will not be drinking anything like sufficient quantities of water. They will also be increasingly less mobile. These two factors alone should alert staff to the possibility of someone with dementia becoming constipated.

Obviously, this is not a complete list but it is given to highlight areas of particular concern. All the other pains, which people will have because of their individual circumstances and conditions, will still be there. The above is given to highlight the need for specific attention and vigilance in these areas as people age and of course when they develop dementia.

Summary

The learning disabled population is, like the rest of the population, ageing. There is concern that this demographic change has not been sufficiently reflected in recent government policy on services for people with a learning difficulty. A consequence of this is that people working within services for people with a learning difficulty are often not sufficiently versed and aware of the conditions of older age. Given this, it is not surprising that people within the learning disability service are not always sufficiently aware of the potentially painful conditions that people may start to experience as they age (NHS Scotland, 2004).

Some conditions are more likely to be encountered than others. Many of the most common conditions were encountered during the research and are described within this chapter.

Recommendations arising from this chapter

- 1 The needs of older age and dementia among people with a learning difficulty are reflected in social policy and planning.
- 2 Staff are provided with training that addresses the needs of older people with a learning difficulty and in particular people with dementia.
- 3 All training should include content on pain and pain management in older age.
- 4 Staff should be made aware of specific conditions that may affect people with a learning difficulty as they grow older.

Overall recommendations are listed in the Appendix.

9 Conclusions

This project set out to examine the pain management needs of people with a learning difficulty who have dementia. This was achieved through interviews with and some observation of people with a learning difficulty, direct care staff, GPs and members of the community learning disability teams. The study found that pain was not readily recognised or diagnosed within this group. The impact of 'behaviour that challenges' within the service, problems around communication, beliefs about pain thresholds and the use of agency/bank staff contributed significantly to a low level of pain recognition. People with a learning difficulty and dementia who were interviewed described their experiences of pain; these were not always recognised by staff. Of particular concern were the references made by people with dementia about the extent to which their pain caused them to wake at night. In a number of sites staff identified the waking solely as a consequence of dementia and so failed to give pain relief.

People with a learning difficulty who are getting older will experience the painful conditions that can accompany older age. There was concern, therefore, that staff were not always sufficiently aware of what these were or of how they might impact on someone with a learning difficulty. There was evidence of a need for staff to be better aware of the conditions such as arthritis that can cause pain.

The role of staff in informing GPs about individuals' changed behaviours, their histories and needs was acknowledged by both staff and GPs as critical to pain recognition and diagnosis.

This raised concerns among both staff and GPs about the use of agency/bank staff, the high staff turnover in some parts of the service and the lack of appropriate training. The study highlighted varied practice between GPs in relation to people with a learning difficulty. There was evidence of some excellent, sensitive and appropriate interventions by GPs. The positive impact of GPs who chose to develop specialist knowledge and experience of working with people with a learning difficulty was described. There was, however, also evidence of GPs who did not appear to be cognisant of the special needs of this group of patients and who provided ill-informed and sometimes insensitive practice.

The role of CLDT members was highlighted as increasingly important, especially in light of their role as 'health facilitators' as envisaged by *Valuing People* (Department of Health, 2001). There was clear evidence that members of the CLDT considered

pain as a possible explanation for changed behaviours among younger people with learning difficulties. This did not appear to be as evident in their work with older people, and especially in their work with older people with a learning difficulty and dementia.

The use of 'as required' pain relief was considered and seen as a treatment route that should only be used with caution. The use of the WHO Guidelines (1996) should underpin and inform the prescription of analgesia to people with a learning difficulty and dementia. The use of non-pharmaceutical interventions was described as being highly effective in either removing the pain or at least in relieving some of the intensity.

The need for training for everyone involved was highlighted. Indeed, the impact of this study was noteworthy in that the intervention of the researchers led to an increase in pain recognition in almost all of the sites studied. This was the result of only an initial visit to explain the study.

It was not within the remit of the study to look at wider systems. The scope was within the primary social and health care system. Throughout the study, however, there was a growing amount of reported evidence about the experiences of people in wider contexts. The experiences reported showed diverse responses to people with a learning difficulty and dementia when they engaged in the wider health care systems. Clearly, this has an impact on the management of their pain needs.

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Appendix: Overall recommendations

A Recommendations to increase pain awareness among all staff

- 1 There must be training on pain recognition for all staff involved with the care, support and treatment of people with a learning difficulty and dementia. The curriculum must address a number of issues including the:
 - subjectivity of pain experiences
 - communication problems caused by the onset of dementia and how these might hinder pain recognition
 - need to consider the possibility that behaviour that challenges may indicate the existence of pain.
- 2 There should also be training about *behaviour that challenges*, which must include training about the way in which dementia affects people and the consequent changes in the meaning of the behaviour.
- 3 Furthermore, training on *behaviour that challenges* must include recognition of the possibility that it may be caused by pain.
- 4 All training should include content on pain and pain management in older age.
- 5 Staff should be made aware of specific conditions that may affect people with a learning difficulty as they grow older.
- 6 There must be a cautious use of agency/bank staff. Staff used from this source must receive the same training on pain recognition as other staff.
- 7 Life-story work must be developed as an essential tool to enable staff to understand the person's past in order to understand their present behaviour. This should be developed for everyone preferably before they develop dementia.

B Recommendations that enable prevention and better management of pain

- 1 Support staff must receive training about the pain needs of people with a learning difficulty and dementia.

- 2 There needs to be a simple, agreed system of recording important information about the individual's pain and its management. This must be used by all staff.
- 3 Support staff need to develop ongoing relationship with identified GPs who demonstrate an understanding of the needs of people with a learning difficulty and dementia.
- 4 Organisations must develop clear and simple protocols that provide instructions and guidance for staff to follow when contacting GPs and other doctors.
- 5 The use of analgesia to manage pain should follow established guidelines (SIGN, 1998; NICE Guidelines, 2004) – this would call into question the current prevalence of 'as required' (PRN) prescription. 'As required' (PRN) analgesia should not be the primary approach to pain management in people with a learning difficulty and dementia. Analgesic prescription must follow the WHO Guidelines (1996) on prescribing. These recommend regular administration and also that treatment should be adjusted from one step to the next according to increasing or decreasing pain severity, history of analgesic response and side-effect profile.
- 6 The use of non-pharmacological interventions for pain management should always be considered.
- 7 Staff are provided with training that addresses the needs of older people with a learning difficulty and in particular people with dementia.

C Recommendations in relation to GP training and practice

- 1 Learning difficulty studies need to be included in undergraduate and post-qualifying education for GPs.
- 2 There should be encouragement for some GPs to specialise in both learning difficulty and dementia.

D Recommendations in relation to community learning disability teams

- 1 Members of the CLDT must have a more heightened awareness of the impact of age and dementia on people with a learning difficulty.
- 2 All staff should receive training on the impact of older age and dementia on people with a learning difficulty.
- 3 Pain in older people with a learning difficulty and dementia should be given higher priority as part of the assessment process carried out by members of CLDTs.
- 4 CLDT members and support staff need to develop regular reviews of older people with a learning difficulty and dementia who are experiencing possible painful conditions.

E Recommendations for planner and commissioners

- 1 The needs of older age and dementia among people with a learning difficulty must be reflected in social policy and planning.
- 2 All of the above recommendations should be taken into account.

