

Pain in Older People



**Reflections and experiences from
an older person's perspective**



The University of
Nottingham



THE BRITISH PAIN SOCIETY

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Reflections and experiences from an
older person's perspective

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A life with pain

Pain is a relatively common experience during life and we are all likely to experience it at one time or another. But what happens when that pain does not go away?

Persistent pain experienced when we are young and active is unlikely to be accepted as something which is 'normal'. Indeed, we are likely to do everything we can to ensure we obtain the best available help and find the treatment most effective to manage the pain.

Such attitudes and beliefs should not change with older age. Yet, pain in older people is highly prevalent and widely accepted as something to be expected and regarded as 'normal' in later life. Hence, suffering associated with persistent pain in older people often occurs without the appropriate assessment and treatment. The impact of persistent pain on older people and on the health and social care system is significant and of great concern. Pain in older people is an increasingly important health issue, and one that requires urgent attention.

This publication aims to highlight the issue of pain in older people by exploring older people's experiences of living and coping with persistent pain and reviewing the literature on pain in older people. It aims to raise awareness of pain in older people, challenge current beliefs and promote the necessary action by all who have the responsibility for, and are involved in, assessing, managing and caring for older people in pain.

The work was conducted between August 2007 and April 2008. We conducted two 'listening events' with a total of 21 participants, discussing with them the main issues and concerns relating to pain in older age. The information we gathered from these events helped us to gain an understanding of what it is like to live with pain in older age and helped to shape the themes in this publication.

Following the 'listening events' we invited several older people to share with us their experiences and thoughts about pain in older age. This publication presents a selection of their stories, as told by them, in Part 1. The authors are of various ages and come from

a variety of backgrounds; all have a story to tell. These people, who regularly suffer pain, describe their experiences and reflections on it. Their accounts are both insightful and inspiring; what they have written is heartfelt and powerful.

These articles, while not necessarily reflecting the views of the older population at large or of Help the Aged or the British Pain Society, reveal some of the concerns, experiences and feelings that older people have in connection with pain in older age. They can be regarded as a tool to stimulate further debate about the experience of pain in older people and to shape services and support to meet the needs of older people living with persistent pain.

Part II is a summary of key literature and policy, highlighting the fundamental issues relating to pain in older people and discussing the implications of the evidence. A summary of the lessons learned from the review and the implications for practice and future policy conclude the publication.

We hope that this publication will provide an insight into the lives of older people living with persistent pain. Without an understanding of the basic principles of pain in older people correct assessment and management cannot be ensured. Pain has a highly detrimental impact on quality of life and is severely disabling. These effects become more pronounced with age, resulting in greater responsibility and costs for the caregiver, care-provider and healthcare system. Ageist and discriminatory attitudes toward older people in pain must be challenged and ended. Pain in older people needs to be seen as a priority. It is not a normal part of ageing. Much more can and must be done to improve help and support.

Executive summary

“Living with pain” is a contradiction in terms. Why? If you are constantly in pain, you don’t have a life.’

Vanessa Wilson, 65

Following a previous literature review including significant research probing the views of older people, Help the Aged found pain to be one of nine issues that must be addressed if older people using health and social care services are to be treated with dignity. Dignity and pain are inherently connected and any effort to deliver dignity in care needs to ensure that no older person suffers pain unnecessarily. To bring this about, the older person must be able to make choices concerning the treatment of their pain and to exert control over how it is managed and who manages it. At the same time, staff should be ensuring that relief of pain is timely and that their own attitudes toward older people are not discriminatory.

Pain is highly prevalent in older people: nearly 5 million people aged 65 and over are in some degree of pain or discomfort. Pain is highly damaging to the quality of life of the older person, their family, friends and carers, and costly for society as a whole, yet pain is not an inevitable part of ageing. It can vary in its duration, intensity and effects as well as in its origin and cause, but too often it is the cause of pain that is the main focus of attention, while the older person’s actual experience is forgotten.

Older people are more at risk of pain than other sections of the population but less likely than younger people to experience good pain management. Various reports have found that pain issues are compounded for care home residents, who are given less priority than people living in their own homes, are likely to have reduced access to GPs and may suffer at the hands of poorly educated staff.

Many health problems result from persistent pain and their impact can be more pronounced with age and increasing frailty. Pain becomes a more complicated issue for the many older people who are affected by multiple conditions and take a range of medications. Furthermore,

normal ageing tends to increase the sensitivity to both intended and unintended effects of drugs. This situation needs to be effectively managed with regular reviews.

The many variables relating to pain in older people make the effects complex. The perception of pain can vary according to external factors and pain does not always behave predictably. Treatments range from medication to light exercise and complementary therapies such as acupuncture. The success of these varies enormously from person to person and may well be influenced by the attitude of the healthcare professional managing the older person’s case.

The provision of specialist pain services varies greatly throughout the UK and older people are rarely referred and treated under programmes specifically addressing the issue of pain.

Assessment of pain is critical to effective management. This is usually done through tools and questions that seek to analyse the experience of pain. However, this depends on older people reporting their pain: this can be problematic as older people can be reluctant to vocalise their experience. Failure to report is also likely to be common among older people with communication difficulties, or conditions such as dementia and Parkinson’s disease. Pain is highly subjective and this, combined with older people’s reluctance to complain of it, means that it is likely to be under-reported.

Also, in order to assess pain in an older person competently, health professionals must be able to effectively observe the experience, particularly if the individual has dementia or another disease that affects their ability to express their discomfort verbally.

Professionals need to proactively find out about older people’s experience of pain and how it impacts their life; they also need more training to increase their awareness of the issues.

'I think it is always wise to pace myself and approach different activities with a little bit more care. It takes a lot longer for me to do things than when I was a lot younger, and I try not to let the pain affect me.'

Fred Basson, 74

Many older people living in persistent pain show remarkable determination to go on living their lives as normal. They require flexibility and planning to do this. As part of their coping strategy, they often tend to restrict their activities, which can lead to isolation and depression and can have further consequences such as breathlessness and pressure sores. Access to community facilities and services for older people in pain is essential to help ease the pain – both directly and to help keep spirits up and provide distraction.

Many older people do not seek help for fear of negative interactions with healthcare providers and of medical treatment. Many also feel let down by the health system and have low expectations of both the system and health professionals. Support and education need to be available to older people to help them manage their pain and to feel in control.

Pain greatly impacts on people's lives but the chance to talk about it is rare. We found the majority of older people participating in our interviews and discussion groups were pleased to be given the opportunity to describe their experiences.

'There's such humiliation in pain.'

Claire Rayner, OBE, 76

Older people explained that pain can strip you of your dignity in public – among strangers on the street, for example – and also damage relationships with close friends and family. Pain is an immensely personal issue, and can be difficult for others to understand, particularly if the older person does not look ill. It can become a barrier to socialising. It can prevent a grandparent from picking up their grandchild.

'It's shameful to live such a way with little way of escape. Over the years I have felt the loss of dignity and [been] left humiliated by pain.'

Vanessa Wilson, 65

This report highlights a lack of knowledge on the part of health and social care professionals about pain in older people, a failure to assess the pain and an underestimation of pain in older people by both healthcare professionals and older people themselves. These all contribute to the unnecessary and unacceptable suffering of older people.

Progress on improving the quality of life for older people in pain, reducing the pain and improving access to pain services will focus on:

- asserting the message that pain is not a normal part of ageing and must not be tolerated
- challenging discrimination and ageist attitudes with regard to pain in older people
- focusing attention on identifying the physical, psychological and social risk factors specific to persistent pain in older age, and
- recognising the impact that pain has on the quality of life, and the dignity, of older people.

Part I

**Articles by older people
about the experience of
pain in older age**

1 Pain – don't tolerate it

I began working as a cadet nurse in a couple of English hospitals before there was an NHS. Later I trained in a large London hospital and ended my bedside career as a sister with 12 years of nursing. So I know a lot about nursing pain and how people behave in these sorts of situations.

I'm 76, which these days is not old any more; it's the tail of middle age. I understand my generation very well. We learned our attitude to pain from British society in general and from our families – it was 'Don't make a fuss'.

The stiff upper lip was not just to do with emotions. It was also about physical distress. As a child, if I fell over, hurt my knee and yelled a bit, I was allowed a moment or two to have a yell, but after that it was 'Come, come, you've got to be braver than this', and 'I'm going to put something on your cut which will hurt. But you mustn't cry – because you're a brave girl, aren't you?'. So I didn't cry, even though I was yelling inside my head. This was an attitude that spread right through society.

I too was infected by the attitude of the people I looked after and was very much the recipient of that sort of learning. I learned not to make a fuss. I never did, and to this day I don't like to fuss about pain. I regard myself as a stoic. However, the difference is that I know something can be done about pain now in a way it couldn't be back at that time.

Having looked after my own aches and pains for a long time, I thought I probably had some arthritis because I was the age to have it. It must have been in the early '90s when one of my colleagues noticed that I was limping. 'What are you limping for? Got a stone in your shoe?' he asked. I told him, 'I often limp. I've got a bit of pain in one of my knees.' He said, 'Don't be daft! Do something about it! Limping only throws everything else out – it ruins your stance.'

So I did, because I thought, well, if it's that noticeable perhaps I should. I went to see a rheumatologist and was x-rayed and checked, after which the rheumatologist told me that my knee was an absolute mess of damage. I'd had the pain and difficulty for a long time and done

nothing about it, because one doesn't like to fuss. But I had to have a new knee, which I did, and I thought, well, that's that – I won't have any more problems. But inevitably, the other knee began to show more problems because the other one was all right, and so I learned to limp the other way. But I didn't delay this time: I went and had the right knee replaced.

Each knee replacement was exceedingly painful and a nuisance. I still have pain in my knees and now I've developed severely damaged shoulders because of arthritis and rather heavy handling by some people who nursed me – I think it was being hauled up the bed by my shoulders that did it.

I've got raw shoulder bone rubbing against bone. The cartilage has gone and all sorts of things have gone wrong. This shoulder pain goes on and on and on. Even now, when I've had it so long, sometimes I forget I've got it and fail to protect it and I'll throw my hand up to someone and, ah, I know I shouldn't have done that! So I do yelp a bit sometimes. It is as bad as that. I'll be really grateful for a new shoulder. But I'm nervous about it. I don't want to finish up in intensive care again and left with a post-traumatic stress episode similar to the three-week one I experienced when I had an operation on my Achilles tendon in the spring of 2003. Ex-patients of the intensive care unit can get very distressed just thinking about it – it's called post-traumatic stress syndrome and I have it.

You can't describe pain. It's intensely personal to everybody, and you can't say what it's like as it varies enormously. All I can tell you is one thing and this is true for everybody: pain is exhausting. It makes you so tired, even if you sit and find a position that's comfortable. Pain makes for general feebleness. I can't walk very far now because the fatigue that comes with pain affects other muscles. I can't write properly. I can't use the typewriter or the keyboard on my computer, because of the pain. It's dreadful. I'm not jumping about as I used to and not wandering around busily, so I'm not expending the energy I think I should be.



However, there's more to pain than just these physical elements. There's such humiliation in pain. Other people are walking cheerfully along the road and you're hobbling. You have to walk slowly. You have to stop and make an excuse or pretend to look in a shop window so that you can put your hand on the window and rest a moment. It's humiliating. I used to walk a lot but can't do that any more. We'd go out, my husband and I, and walk miles. That's the sort of thing that you miss, and that too has pain in it, the pain of regret and of loss. I've lost important abilities that I used to have, and I miss them.

So pain comes in lots of different ways. It's not just the physical and social aspects – it's the emotional ones.

You become so tired, bad-tempered and frustrated. Pain has become a miserable part of my life that I would do without if I could. But it is possible to learn to live with pain with the right help to teach you about how to use painkillers, what sort of exercise is very helpful which you can have access to, and even choosing what to wear. I'm very careful about my garments. If they're heavy on my shoulders they increase the pain, so my coats are very thoughtfully chosen so that they don't hang on my shoulders and hurt me.

Pain is a warning system. It demonstrates that there is something not right, that a doctor should investigate, and if there is no cure, either pharmaceutical or surgical, the doctor's advice will show you how you can be helped to cope with it. Pain can be your friend – a friend who is telling you to get that advice and help. So don't think pain is all bad. It's there for a purpose. So do listen to it, because it can't fulfil its purpose unless you do. Older people should always remember that pain is not just something you have to tolerate.

Claire Rayner, OBE, 76, is a British journalist best-known for her many years' service as an advice columnist. Her OBE was awarded in 1996 for services to women's issues and to health issues. She is president of the Patients Association.

2 I don't want to be a burden

For most of my adult life I have suffered from back pain. However, this is not surprising when you bear in mind I have had a very manual work life. I spent my early teens working in a coal-pit, and nine years in the army followed by 33 years as a manual worker in a factory. By the age of 58, the pain I was experiencing had spread to my knees and other joints.

I come from a generation which puts up with pain and ailments as part of life. However, it was the extent of the pain, which was making my work life harder to accomplish, which motivated me to see the doctor.

After various tests, including x-rays, I was diagnosed with osteoarthritis. I was given painkillers, anti-inflammatory [medication] and support bandages for my knees. This helped a great deal. The pain could be controlled. However, I am always conscious that the treatment may have treated the symptom of pain, but did not sort out the underlying issues of what was causing it.

It is undeniable that the pain has progressively got worse. The whole left-hand side of my body can become racked by pain. The osteoarthritis is now increasing in my knees, ankles and shoulder. It is a hard pain to describe. The closest description is a dull aching sensation in the joints and bones. This can increase in intensity. I also get the sensation of friction in my joints.

The pain is caused by wear-and-tear – the joints becoming deteriorated. I see pain as part of the 'growing older' process. I think pain is something many older people expect to incur later in life.

One of the main problems I encounter is not the pain but the instability I now have in my legs. My knee can give way at any moment. This means I have to be increasingly careful when coming down stairs. It also means I am unable to pick up my grandchildren as much as I would like.

Simple tasks like lifting a grandchild from their cot and bringing them downstairs become a cause of concern, as I am conscious that if my knee goes an accident could easily happen.

I had to semi-retire at the age of 59 because of arthritis. I miss the manual work I was once able to do more freely. Now, at the age of 67, I have been fully retired for three years. I still enjoy working in the garden and engaging in hobbies like making garden furniture. If I get a delivery of wood, I have to control the amount of work I do. If I do too much work, the subsequent days can be very painful and I can be confined to bed.

Another adverse affect of the pain is that I am unable to participate in family activities as much as I would like. After working hard all my life, I have looked forward to holidays and days out with family. However, I now have to take into consideration my health and pain before any trip.

Later this year my wife and I will be celebrating our 46th anniversary. We have the opportunity to go to New York for a long weekend with family and friends. However, I simply cannot endure the flight. If I were to sit for an extended period, such as six hours, in a confined space, I would be unable to walk far for the next two days. I feel I would be too much of a burden to the others if I were to go.

The pain can be mentally draining, which makes me tired. If I have to sleep during the day this can confuse my sleep pattern and I can find myself waking up at 4am unable to return to sleep. Or I have to go to bed before 8.30pm, missing out on socialising with the family.

How do I try to control the pain? The painkillers are the main solution. I can take a maximum of eight each day, but in extreme cases I may find a few more are necessary. I can get through about 90 tablets a month. I enjoy a drink of cider to unwind most nights. If I am in particular discomfort I may have an extra pint – it numbs the pain more effectively. It is rare for me to do this, though.

I also believe that keeping my weight down helps me to limit the pain, as carrying less weight puts less strain on the joints. I also try to rest for two or three hours midday – this gives my joints the chance to rest. If my joints are very bad, I may have to spend the entire day in bed. This helps with my pain and means I am not burdensome to my family.



The NHS has offered me further treatment, e.g. injections into joints. Also, I am constantly nagged by my family to enquire about joint replacement. However, I am a stubborn old man who does not want to be knocked around.

I come from a generation that views hospitals with suspicion. I have friends who have been in hospital for back and knee operations but the procedure has gone wrong. This makes me less inclined to seek further medical attention. However, I have to say that I cannot fault my GP's care. He seems very in tune with my medical needs. Plus, at the moment, I feel able to control the pain to some extent. Though it is getting worse, I live a good life, so long as I medicate, rest and listen to my body. I am not ruling out getting further medical attention, but if I did it would be more for my family's sake than my own. My wife will not agree with me suffering unnecessarily for the rest of my life when I could have an operation that could give me less pain and more mobility.

One of the largest fears about increased pain is that of becoming a burden. This would be one of the main reasons I would pursue a medical procedure. For the time being, it is not an option I wish to pursue.

All in all I don't feel I have the right to complain too much. There are people younger than me in more pain and with limited life expectancy. As I head towards my three-score years and ten I can see that my body has served me well during my life.

Ben Kelk, 68, father of five and retired security officer, lives with his wife and son in Derby.

3 The emotional side of pain

It's very hard for me to actually give you a time when the pain started because it has been from various causes. When I look back, the arthritis must have started at least 20 years ago in that I used to have quite bad neck pain – which of course one puts down to lying awkwardly or being in a draught or something like that, but gradually you realise it's because of wear and tear.

It's a pain that varies from a stabbing, like a hot knife going through a joint, to something like a continual pressure that [makes] you want to try and move the joint and get rid of it, but it just doesn't go; and on some days it's a continual dull ache. Nowadays, you're always asked to rate pain on a scale of one to ten, and that is very hard to actually say. It's hard to describe it because it's not always the same. With arthritis, it is so variable.

And together with the pain, depending on the severity, goes the depression, because I do find it's a very depressing illness. When you've got something, you're constantly feeling, knowing, that it's always going to be with you. If I wake up in the morning and I think to myself, 'Just at this moment I'm not in pain. I don't want to get up. I'm not going to move. I want to stay here,' it can make getting up really very difficult.

I think what worries me the most about pain is how it takes over and becomes the centre of your life. The rest of your life revolves around the amount of pain you've got. Whether you can go out with your family or go on an outing or just go to the shops depends on the amount of pain and what effect it's having on you at that moment in time. My life is becoming more and more dominated by the amount of pain I'm in. It shouldn't really be like that.

Pain is not a visible illness. It's not an obvious thing to anybody else, and therefore people aren't sympathetic. The only person I can really speak to about my pain is my partner, who I live with, and he, of course, like any partner who loves the other one, finds it hard to see somebody in pain. And the only way he can sometimes cope with it is to pretend it's not happening, and therefore doesn't always appear

to be being very sympathetic. But underneath it's because he doesn't really know of anything he can do to help, and because he feels helpless in that situation he tries to shut it out.

That makes me feel lonely. I want to be able to say to him, 'Look, I'm hurting here' or 'I'm hurting there', but I can't always do that. Not because if I said that he wouldn't sort of try and help me physically, because he does. I mean, there are times when he has to help me dress and that sort of thing because I can't use my arms as I should, and he's perfectly willing to do that. But I think it's the emotional side of the pain that he finds hard to accept and, as I say, that does make you feel a little bit on your own. It's not something you can ever talk to your doctor about in great degree because (a) he hasn't got the time and (b) I just have this feeling that doctors think, well, pain is part of old age anyhow, so take the tablets and keep smiling.

I feel reluctant to keep going and pestering my doctor about my pain because when you get to my age, and especially if you're a woman, you feel he's going to think I'm being neurotic, and because pain can't be seen, it's probably not easy for him to actually understand how much pain I actually am in. Because I've had several things wrong with me, he's seen me quite often, so I have this feeling that, oh, if I go and complain again that this is hurting or that is hurting, he's just going to think, 'Oh dear, not her again!'. So you try to manage it yourself, which I do. I do try to take my medication regularly and as I should do. Although it's something that goes very much against the grain to take so many tablets... I don't like the fact that I need them – it is a constant reminder that you've got pain.

Pain is just part of growing old. One should expect that as you grow older things wear out and don't work as well, and the consequence of this is pain, and that probably you should just grin and bear it and get on with it and not be a miserable old lady, which a lot of people regard you as if you *do* complain about your aches and pains. As they say, you don't make friends by telling people about your aches and pains, do you? Nobody really wants to know or discuss it



to any length. And that's quite difficult because your life tends to revolve around pain and yet, at the same time, it's not something that's seen as being something you can talk too much about. This is why I use the word 'lonely', and I think pain can make you feel lonely because you feel that you're the only one who is suffering and can cope with it, and that is a lonely experience.

Very often, with many experiences in life, we can share them with somebody or we can get somebody else to help us make it better, or they can make it better for us, but chronic pain is something which nobody really wants to know about and this results in a feeling of 'you're on your own'. It would make a difference if there was somebody who really understood what it was like to be in pain and would be available to talk to when it was really getting me down.

Janet Allcock, 73, is a retired healthcare worker and housewife living in Eastbourne.

4 Emulate some sort of normal life

In 1969 I had a bad fall and cracked my coccyx. Ever since then I've had the odd bit of trouble with my back. This worsened in the late '80s, and then about 14 years ago I developed constant sciatica and neuropathy problems. In the throes of all of this I developed temporal arteritis and I was on a high dose of steroids for nearly two years. I'm still on them as a maintenance dose but my bone density has started to drop as a direct result. I've also got arthritis in my right hip and my knees and my ankles and all the rest of it. In other words, I'm absolutely marvellous but my body's dropping to bits. So that's the background.

I think from a pure pain point of view age starts to exacerbate the problems you've already got. In themselves the mild arthritic problems expected to develop at my age probably wouldn't have been as much of a problem for me if I had not already had spinal problems.

At my worst, I felt I was walking on broken glass in my shoes all the time and down the side of my calf felt like my skin had been burnt. It had got to a stage where when I got out of bed to put my foot on the floor I just passed out. I'd gone past my own pain tolerance at that stage.

My GP has been absolutely wonderful. I discuss my pain with my GP. She really is good: she listens. So I feel I can talk to her quite openly about it. She helped me with my drug regime and referred me for acupuncture, which was a tremendous help. However, I cannot talk to the family about my pain. I'm in the position where I have a 94-year-old mother who, although she has some arthritic problems, was until the last two or three years extremely mobile for her age. So of course my children and grandchildren have grown up with this 90-year-old fit nana. To compare me with her they think, 'Well, what's wrong with you?' I tried to discuss it with them at the beginning but it's a non-starter. It doesn't help the relationship and they don't really want to know, so why spend time talking about my aches and pains? No point. It's not going to improve them.

Pain affects my life socially a great deal. I had to stop swimming because it became detrimental

to my condition. I was devastated because that has been my only constant exercise. Even when I couldn't walk a long way I could swim, but that's had to go. Along with it also goes the social side – I'd started to make friends at the pool and get to know people.

Pain is isolating, because you can't join in with things. To go out to a theatre or a concert or something like this, I never know, it's the unpredictability. If I'm in a good spell, great. If I'm in a bad spell, it's a non-starter. My husband bought tickets for us to go to the theatre for my birthday last May and I had to back out because I started in a bad spell before we went. Socially pain does affect you, very much so.

It affects relationships in that you don't want to make a fuss when you go out. If I go somewhere I have to take a cushion because I can't tolerate a hard seat for any length of time. That, at my age, is embarrassing, because I'm comparatively young to have my body in this state. It also obviously affects a marital relationship quite badly. There are times when you'd love to have a normal married life and make love but your body won't let you.

It's the day-to-day effects of pain that I find frustrating. I can't clean my own house any more and that really drives me mad. I do what I can within my capabilities, but things are not the way I used to have them, which is frustrating. So pain can make you feel angry and depressed. Then you sort of pick yourself up, shake yourself and say, 'Look, it's not going to go away – get on with it.'

It's the little things that annoy – not being able to paint one's own toenails, essential with summer sandals! Two walking sticks mean I can't hold my grandchild's hand. Small things – yes – but they matter.

I can't pick out a single method I use to try and cope with my pain. It's a combination. I've got my own sort of pecking order. When I start to get really bad I'm obviously increasing the paracetamol. If I get even worse, I introduce my TENS machine into it. Then I start with my gels, after which I start with the stronger painkillers. So it's really balancing a cocktail of the



medication that I have with the physical aids that I have. And to sort of get up and walk about and try and keep mobile, I go to hydrotherapy. I have acupuncture. They are all means of coping with pain, to try and emulate some sort of normal life.

I've found attending support groups a great help. Once I went to an expert patients' panel that was run at the local hospital, and it was an eye-opener. It was wonderful. So many of us there had common pain problems – like not being able to read because you could not hold your book or keep your head down to read. Solution: use a music stand. Simple solution, but it only came out because there was a group of us discussing it together. I came away from the course with an awful lot.

Doctors sometimes see us as an illness rather than a whole person. You can go to one consultant and they are really good in their own field, but they haven't got a clue what's happening to you elsewhere, and sometimes the things can be interrelated. I'd been going absolutely demented with head pains for over three months, and it was being put down to the arthritic condition in my neck, cutting off the blood supply and all this sort of thing. It wasn't. It was only when I started to get visual problems and my eyesight went that I ended up in A&E and was diagnosed with temporal arteritis. That is a perfect example of it being put down to an age-related illness and not looking any further.

Our age group does get left behind by the NHS in many ways. In some respects you've got to say, 'Well, fair enough'. If you've got a 40- to 50-year-old needing new-type treatments and they're costly, you're not going to give them to somebody who is sort of 65-plus. And that's life, isn't it?

Dorothy Bristow, 68, is a member of the Hull & East Riding branch of BackCare: the Charity for Healthier Backs, registered as part of the National Back Pain Association.

5 I just have to do what I can

I started to get a lot of pain about seven years ago. It started as tennis elbow and then severe shoulder strain. I had to have an operation four years ago and then again last year. But even after this, I still get pain. I find that when I am moving about a lot that is when I notice I become very sore. For example, I suffer more from pain when I move my shoulder a lot.

The last couple of weeks I have had really bad pain in my neck, which was making me feel crazy and I was unable to drive. Now the pain has moved from the neck and I feel much better.

I do know that if you get pain you should go to the hospital or get help, but I don't, because my pain doesn't stay on any one side or part of my body; rather, it seems to be moving all over my body. It will often start from my head, and then come into my neck, down my back and round my waist. So I just stay for a few days in pain and I try to do my best to limit my movement until the pain has moved on.

I'm not sure whether it is because I am from Bangladesh or whether I did not look after myself when I first came to England, but my pain especially gets very bad when it is cold. So I am always on guard and try to do my best to limit my movement and keep my body warm. I have to stay extra warm because it hurts more in the cold. I find it very difficult, especially during winter.

The pain is a numbing, throbbing pain, which can make me feel sick and gives me a headache. I become very moody and it makes me feel unhappy when I have the pain. Sometimes I get quite angry because of pain and irritated at other people, so this can affect my family and the way I am with them.

Pain makes me very weak and I can't do many things I would like to. I rely on family to lift heavy objects and try not to do activities that involve repetitive movement. I cannot do gardening or activities I like as much now.

I worry a lot about my pain and sometimes I think what I have done in the past and can no longer do for myself or for my family. I know that worrying can bring your health down, but

I can't help worrying about it. I find it very difficult to sleep and I am not able to sleep on my side – some nights I cannot sleep at all.

To cope with pain I just have to do what I can. If I go to the doctor he will give me painkillers. So I take painkillers when I need to and my children buy me heat pads. I also used a heat rub sometimes.

In the 1970s, I remember I had a very good doctor when I used to live in Southall. He was a Bengali man and I could talk openly to him and felt very happy to explain to him in Bengali about any problem. He would listen to me and explain in Bengali to me what I had to do or what medication I would have to take. But eventually he moved and now I have a doctor who I speak English with, so it is more difficult to explain what the pain is like as I don't speak good English. I try my best to talk to my doctor and I ask him to kill the pain forever. But I don't like to bother him all the time. My doctor is good but sometimes I feel I see him too much and he has no patience for me or my problems.

My children and wife do what they can to help me but I do not really talk to anybody about my pain. Sometimes I feel like I am a bother to people and they just want me to take painkillers and not bother them.

Nur Uddin, 70, originally from Sylhet, Bangladesh, lives with his wife and family in Coventry.



6 I don't like having to take a lot of tablets

It must be in the '80s, '90s, or something like that when my pain started. I can't quite remember. It started with a pain I used to get regularly in my right heel and I wondered what it was, so I used to tip on my toes. And then eventually it worked its way up from my heel, to my knee.

I thought, 'Oh dear, what's wrong?' When I sat down and went to get up, like on the bus, it used to be ever so painful. So eventually, a while afterward, I went to the doctor's and he said that I had arthritis, which moves about your body, and inflammation of the joints. I can't remember if he prescribed anything for me at the time, but by then the pain had moved from my right leg to my left and I noticed from time to time my hands hurt.

My lower back has begun to be affected with pain as well. It has been so painful, I went to the toilet one night and it was such agony getting back to my bed that I couldn't get in my bed. I just went lengthways in the bed, I couldn't do anything more. It was that painful. But that went for a while and I noticed it came back some weeks ago. When I got up in the mornings, I couldn't tidy my bed because I couldn't get around it. That morning, it was paining so much I cried. My back was hurting so much I couldn't hold up straight and I'd be walking like an old person.

So I sit in my room with my hot-water bottle to my back and it eases the pain, and also I've been taking some co-codamols. They're very biggish and I dissolve them in water. But I will only take those if I am in a lot of pain and that seems to ease the pain.

I don't like pain. Well, nobody likes pain, and because it's consistent I don't like it. It makes you feel low. I don't sleep at all at night. I don't know why but I'm tossing and turning all night.

The pain can be very intense and other times it's not. The pain comes and goes, and it hurts me off and on. It's either in one place or then it goes to another. It's an annoying pain – that's all I can say to describe it.

Sometimes I'll take tablets. I don't like taking a lot, but if I've got to take it, I'll take it. And that's what I have been doing.

Growing up in Barbados, I come out of a family that was hardly ever ill. I've never seen people have so many different pains until I came to England.

The sickness back then was different to now. When I was growing up in Barbados we used to use a lot of herbs and salts for sicknesses. You would hardly ever go to the doctor, unless it was serious. So no one ever really went to the doctor much at all. All I could remember was my mother having period pains, and she never went to the doctor but used herbs. I mean my grandmother lived until she was 93 years old and she was hardly ever ill. She had a good memory and her eyesight was ever so good.

Where tablets were concerned, we would use a lot of herbs instead because you would just go and pick, wash and boil them. If you had any sickness or pain you would take that and it seemed to stop it.

And if you got a cold, we do a lot of greasing with oils, and then you take some sort of herb. Or you might go to the chemist and they'll get you a bottle of cough mixture and you take that. But when you finish taking that, we used to take a good rousing dose of castor oil, and it seemed to move the cold from your lungs. That sort of thing we would take for sickness.

So I don't know if it's by not seeing a lot of illness in the family or having to take a lot of tablets which is why I don't like having to take a lot of tablets.

I mean, if someone has to take a lot of tablets, to me, each tablet is made up of a different ingredient, so how they don't clash when you take so many, I don't know.

I have never been to the doctor's a lot. I only started going to the doctor because of my arthritis, but where I am concerned, from the time I came to England we always had good doctors that was really interested and concerned about us.



Pain in Older People

Usually if I talk to anybody about my pain it's with friends who are going through the same thing as me, since if they're going through the same things they would understand.

I find if the pain is severe and I'm laid out, unable to get up, I would be thinking all the time about the pain and concentrating on it. Once I can get out, it takes my mind off it. So when I can get out I seem to manage better. Perhaps if I couldn't get out, or if I had to walk with a stick, I think it might affect me more.

Pain hinders some older people. Sometimes you see them walking, in a lot of pain, and very often they've got a stick or something like that. But where I'm concerned I cry more not because of the pains, but because I am on my own. I think if you live with the family it eases having pain since it takes your mind off it and because you've got somebody there to comfort and help you.

Pain is not part of growing old; I think it's because of what is wrong with you. That's how I feel.

Doreen Elcock, 82, mother and grandmother, born in Barbados, lives alone in Nottingham.

Part II

Evidence and discussion

1 Messages from the research

The section is a summary of the literature and policy that highlights the fundamental issues relating to pain in older people.

Table 1 An introduction to defining pain

Pain is defined by the International Association for the Study of Pain as *'an unpleasant sensation and emotional experience which is associated with actual or potential tissue damage or is described in terms of such damage'*.¹ It is a very complex and subjective experience influenced by various biological, psychological and social factors.² The concept of 'total pain' was defined by Dame Cicely Saunders as the suffering that encompasses all of a person's physical, psychological, social, spiritual and practical struggles.³

Acute pain

- Pain which persists for a short time.
- A temporary sensory experience which can be of benefit, warning the individual of possible tissue damage or injury.
- When severe it can have negative physiological and emotional effects.⁴
- The intensity of the pain is often reduced after appropriate assessment and treatment of the pain causal factor.⁵

Persistent pain

- Pain which persists for many weeks, months and years.
- Defined by the International Association for the Study of Pain as *'continuous or recurrent pain that persists past the normal time of healing, most commonly about three months' duration'*.⁶
- Often of unknown cause or the result of long-term conditions.
- Multidimensional in nature,⁷ with no beneficial properties.⁸
- Difficult to treat effectively; requiring a variety of approaches to relieve and modulate the pain.⁹

Epidemiology of pain in older people

Current evidence implies that older people are more susceptible to the experience of pain than any other sector of the population.¹¹ National UK statistics report approximately 50 per cent of people aged 65 years and older are in some degree of pain or discomfort¹² – nearly 5 million older people.¹⁰ The proportion for the over-75s increases to 56 per cent of men and 65 per cent of women.¹² This equates to over 1 million men and nearly 2 million women, which is illustrative of the gender differences in pain across age groups.¹³

The prevalence of pain in institutionalised care settings is a particular cause for concern, given that older people are the main users of such care.¹⁴ For instance, the prevalence of persistent pain in older persons living in a care home setting is estimated at 45–80 per cent,¹⁵ thus highlighting that persistent pain in older people is widespread and problematic in these settings.

Research suggests that 70–90 per cent of people with advanced cancer experience persistent pain.¹⁶ The incidence of cancer rises with age, with one estimate indicating that individuals over 65 are 11 times more likely to develop cancer than younger people.¹⁷ Pain is therefore a priority in the care of older people with cancer.¹⁸ The extent to which cancer pain is relieved during this stage of life has long been understood to have a profound impact on quality of life.¹⁹

Table 2 Cancer pain

Individuals with cancer experience both acute and persistent pain syndromes, which are associated with their tumour or with another painful condition unrelated to it. Most acute pain problems that cancer patients encounter are caused by common diagnostic or therapeutic interventions. Moreover, many cancer patients with well-controlled persistent pain have transitory 'breakthrough' pain.²⁰ Persistent pain experienced by cancer patients may be the direct result of the type of cancer that they have, or it may be related to therapies administered to manage the disease or to disorders unrelated to the disease or its treatment.²¹

Pain is one of the most common reasons for seeking medical attention and for hospital admission.²² Older people are the main users of health and social care services, with Hospital Episode Statistics (HES) reporting that over a third of all admissions to NHS hospitals in England are people over 65. It is estimated that at any one time the over-65s will occupy about two-thirds of hospital beds.²³ Further statistics indicate that the over-60s are likely to stay more than twice as long in hospital for conditions associated with persistent pain than those aged 59 and under.²⁴

While pain management has advanced significantly in recent decades, older people remain less likely than younger people to receive good pain management,²⁵ with older women and those from ethnic minority groups being more at risk of under-treatment than white older men.²⁶

In addition, the UK population is ageing. It was estimated in 2006 that the proportion of people aged 65 and over will increase by over a third, from 16 per cent to 22 per cent, by 2031. Hence, for the first time in the UK, by 2025 the number of over-60s will have passed the number of under-25s.²⁷ These statistics highlight pain in older people is an increasingly important health issue needing greater recognition and attention.

Effects of pain in older people

The evidence of age-associated differences in the prevalence, severity and impact of persistent pain demonstrates that the effect of ageing on an individual's experience of pain is complex.²⁸ For example, research examining the effect of older age on pain thresholds – the point at which a person becomes aware of pain – is ongoing, with several studies indicating an increase in pain thresholds with older age.^{29, 30} Similarly, Lautenbacher *et al* conducted a comprehensive survey on age-related changes in pain perception, concluding that the perception of pain in older people is likely to alter according to stimulus-specific changes.³¹

Pain in older people is often atypically manifested. For example, pain may be absent when normally expected to be present; when pain does occur it may be ill-defined or poorly localised, persisting

longer than a younger person would expect it to.³² So while the management of pain in older people is a major concern, attention must also be paid to the absence of pain in older persons where under normal circumstances pain would be present, because neglecting any warning of impending problems in older people could result in greater long-term persistent pain.³³

Table 3 Older people's thoughts on pain

- 'Pain changes you completely... It just takes your life away. Your whole personality changes.'
- 'It does affect your self-esteem because you always think about – well, I know it's negative thoughts really that you shouldn't have, but it's very difficult not to sometimes. But you think about the things that you did do and you were a very sociable person.'
- 'Pain is exhausting... You have to walk slowly. You have to stop and make an excuse or pretend to look in a shop window so that you can put your hand on the window and rest a moment. It's humiliating.'
- 'If I go somewhere I have to take a cushion because I can't tolerate a hard seat for any length of time. That, at my age, is embarrassing, because I'm comparatively young to have my body in this state.'
- 'Pain is frustrating because you can't do things for yourself... Everything's a challenge.'
- 'Pain is deep in my side and when it's really bad I'm not able to breathe deep, because when I breathe in deep it hurts.'
- 'I get very depressed and anxious about it... it's frightening, especially when you live on your own.'
- 'Pain can make you feel lonely because you feel that you're the only one that is suffering and can cope with it, and that is a lonely experience.'

Extracts taken from 'listening events' and interviews held with older people who suffer pain



The substantial health and social problems resulting from persistent pain in the general population are well recognised, including helplessness, depression, isolation, family breakdown and disability.^{34,35} The impact of these problems becomes more pronounced in older age.³⁶ In addition, further consequences of persistent pain in older people include the loss of functional dependence, impaired muscle strength, limited mobility and physical performance, breathlessness, depressive symptoms, emotional distress, disturbed sleep, social isolation, suicidal tendencies and higher mortality rates.^{37, 38, 39, 40, 41}

The problems arising from persistent pain that many older people experience and the detrimental impact on their quality of life are incontrovertible. This results in greater responsibility, cost and resource for the care-giver, care-provider and healthcare system.⁴²

Following a previous literature review including significant research probing the views of older people themselves, Help the Aged found pain to be one of nine issues that must be addressed if older people using health and social care services are to be treated with dignity. Dignity and pain are inherently connected and any effort to deliver dignity in care needs to ensure that no older person suffers pain unnecessarily. To bring this about, the older person must be able to make choices concerning the treatment of their pain and to exert control over how it is managed and who manages it. At the same time, staff should be ensuring that relief of pain is timely and that their own attitudes toward older people are not discriminatory.

Key issues for assessing pain in older people

If pain is not recognised it cannot be treated. Assessment of pain is the prerequisite for successful pain management. Difficulties arise when assessment is inadequate, and also because of the highly subjective nature of pain and the difficulty in defining atypical manifestations of pain.⁴³

Self-reporting is the standard method for identifying pain.⁴⁴ Simply worded questions and easy-to-understand tools are designed to assess the sensory and emotional experience of pain and the impact it has on the physical, functional and psychosocial aspects of the individual's life. Important components of assessment include the use of pain intensity scales, pain maps and observing physical activity and behaviour.⁴⁵

However, concerns persist regarding the effectiveness of using any one multi-dimensional tool to assess pain in older people, with a recent systematic review of literature on the assessment and management of pain in older people by Schofield emphasising the need for further work to investigate pain and behavioural pain assessment scales.⁴⁶

Additionally, an older person's ability to self-report may become increasingly compromised as a result of impaired cognition and communication; the detection and management of pain can

therefore become severely distorted.⁴⁷ Factors including dementia, some forms of stroke, Parkinson's disease and/or language and cultural barriers may cause such difficulties.^{48, 49}

Older people demonstrate greater self-doubt than younger people and are less inclined to vocalise their suffering of persistent pain.⁵⁰ In addition, older people use different definitions and descriptions for pain – different words, phrases and similes from those used by younger people – often describing their pain in a way that understates their condition.⁵¹ Therefore, the true incidence of persistent pain in older people is likely to be under-reported and misrepresented.

When older people are unable to self-report their pain, pain assessment relies on observing pain-related behaviours. A systematic review conducted by Zwakhalen *et al* regarding behavioural pain assessment tools for use with older people who have severe dementia concluded that none of the current 12 behavioural pain assessment tools are convincingly appropriate for these patients.⁵² Further, a recent study by Kerr *et al* found that pain assessment in older persons with learning difficulties or dementia was more difficult when the healthcare professional is unfamiliar with the older person and believes, incorrectly, that people with a learning difficulty or dementia have a higher pain threshold.⁵³

Older people not wanting to report their pain, and nurses or carers failing to enquire about it, causes barriers to pain management in older age.⁵⁴ Therefore, it is important for practitioners to routinely enquire whether pain is affecting the patient's ability to perform everyday activities, and to incorporate direct observation of physical performance into the clinical assessment of older people.⁵⁵

Comprehensive age-appropriate pain assessment tools are required to ensure adequate pain detection and measurement in older people with learning difficulties and dementia. These assessment tools must consider a wide variety of cognitive and behavioural influences;⁵⁶ identify both verbal and non-verbal cues of pain;⁵⁷ and

include several observer-rated scales of behavioural pain indicators⁵⁸ combined with historical and physical examinations.⁵⁹ Greater education and training on this subject are vital to enable healthcare staff to effectively understand and treat the complex sensory and emotional experience an older person in pain suffers.⁶⁰

Table 4 Living with pain in older age

- 'It's dreadful. I'm not jumping about as I used to and not wandering around busily, so I'm not expending the energy I think I should be.'
- 'Unless you have the same pain yourself, or similar pain, nobody understands. So a lot of people, they just have no concept at all. They don't understand what chronic pain is. They just think if you've done something to your back it gets better and why are you still like this? And I must say I have met that opinion quite frequently.'
- 'Your brain's still so young in there. So I find it hard to accept pain. Why should I have pain because I'm getting older? There are a lot of people that haven't got pain that are older.'

Extracts taken from 'listening events' and interviews held with older people who suffer pain

Key issues in managing pain in older people

The experience and consequence of pain for each individual changes with time. Older people are more likely to experience a variety of medical conditions requiring management of a range of symptoms.⁶¹ The management of these symptoms may result in polypharmacy, making older persons more susceptible to adverse drug reactions due to the physical changes of ageing and occurrence of multiple medical problems.⁶²

For example, normal ageing and associated organ dysfunction tend to increase sensitivity to both the desirable and the adverse effects of most drugs. Reduced renal function, altered volume of distribution and a range of other



factors can result in elevated levels of free drugs for older persons and an increased potential for toxicity.⁶³

The long-term use of analgesics is known to be potentially problematic for older people, with a significantly increased risk in older people, compared with younger age groups, of adverse reactions to analgesics and age-related differences in response to analgesia.^{64, 65} Therefore it is important that analgesic treatment is tailored for older people, with awareness needed of co-existing medical conditions (co-morbidities) and the higher prevalence of sensory and cognitive changes with older age.⁶⁶ The increased risk of multiple co-morbidities and polypharmacy in older age requires the development of multidisciplinary pain management strategies. Such strategies for older persons can be improved by further research in clinical practice to investigate age-related differences.⁶⁷

Inadequate management of pain is the result of various factors, such as deficiencies in the education of physicians and other health professionals in pain control and palliative care; fear among health professionals of drug dependence and addiction that results in under-

prescription and under-use of analgesics; lack of general awareness that pain can be adequately controlled and inappropriate availability of suitable drugs.^{68, 69}

Older people in pain differ from younger people in pain. Persistent pain in older people is more likely to be caused by an underlying chronic condition⁷⁰ – a reflection of the well documented age-related increase in the prevalence of regional and widespread conditions such as osteoarthritis,⁷¹ myocardial ischemia⁷² and cancer.⁷³ Despite specific treatments, the presence of persistent pain in older people continues owing to underlying degenerative and chronic diseases.⁷⁴ A study by Zyczkowska *et al* of pain in community and institutional settings found that those who are of advanced age are significantly more likely to receive less potent medication than younger homecare clients, since physicians are reluctant to use higher levels of painkillers in older age.⁷⁵ The reluctance to prescribe and administer strong analgesics to alleviate pain at the end of life following the Shipman case is known as the 'Shipman effect'. While the exact effect of the Shipman case is debated, the fact remains that if older people do not receive appropriate

pain relief at the end of life, they risk dying in pain – which is extremely distressing, not only for the patient but also for any family members who witness the death.

Therefore, the educational and emotional needs of the older person, as well as any informal carers, friends and family, need to be taken into consideration in order to maximise the effect of pain management strategies.

Key issues in care homes

A recent review of pain assessment in older people by Schofield revealed that research exploring older people's experiences of persistent pain in community settings is limited. Such research could help to inform and guide policy and service development.⁷⁶

A recent report published by the Patients Association indicated that many older people in care homes were not given the same medical priority as people living in their own homes; efficient medical management was lacking in the care home setting; and the incidence of self-administration of medicines by residents was low.⁷⁷

The report further identified a lack of direct contact or dialogue between residents and the person responsible for prescribing their analgesia, with residents rarely seeing their GPs. In addition, structural organisational issues, a high staff turnover and a lack of education were highlighted as adversely affecting pain management.

Further factors contributing to the inadequacy of pain management in the care home setting include inadequate assessment by healthcare professionals, reliance on non-professional staff, a lack of staff education and training in pain assessment and management skills,⁷⁸ and the high prevalence of cognitive impairment among care home residents.^{79, 80}

The *My Home Life* report and programme, which is working to improve the quality of life of older people in care homes, acknowledges the detrimental effect of pain on the lives of older people in care.⁸¹ The standard of pain

management in care homes urgently needs to be improved, to ensure the well-being, and the dignity, of residents.

Approaches to pain management in older age

A research study by Blomqvist and Edberg reported that living with persistent pain was not necessarily deemed, by many older people, to be an obstacle to living a satisfactory life. Older people often consider the consequences pain has for daily living to be a greater problem than the pain itself.⁸²

Remarkable determination is shown by older people to get on with their lives as well as possible by adapting to pain and modifying their activities to limit the probability of pain.⁸³ Advanced planning is vital for older people to be able to persevere in having as meaningful a life as possible despite their persistent pain.⁸⁴

However, many older people in pain are less able to adapt. It must therefore be recognised that older people who are no longer able to cope positively with their pain cannot be viewed solely from a biomedical perspective, since medical treatment alone is no longer sufficient to successfully manage pain. Hence, the concerns of older people, including the physical, psychological and social variables affecting them, need to be taken into consideration when examining persistent pain in later life.⁸⁵

The importance of non-drug treatments to alleviate pain in older people must not be underestimated. Although various non-drug treatments still require empirical evidence to support their use, many have been found to help relieve and reduce pain in older people; including moderate exercise, transcutaneous electrical nerve stimulation (TENS), acupuncture, distraction, relaxation and holistic techniques. Yet there is limited access to information on complementary and alternative pain management solutions for older people, or their carers, and as a result they are not widely used in the community.^{86, 87}



Studies have found that older people in pain tend to limit their activities – resulting in lower self-sufficiency and lower physical performance,⁸⁸ both of which have been linked to being predictors of depressive symptoms and suicide in older people.⁸⁹ Lack of mobility and activity can further lead to an increased risk of pressure sores, breathlessness, frailty and, hence, further suffering.⁹⁰ In some instances, moderate physical activity and leisure activities including walking and gardening, housework and distraction techniques have proved to be beneficial for older persons with functional limitations and health problems. Furthermore, moderate physical activity in older age is known to have a beneficial effect on survival, helping to reduce the risk of early mortality.⁹¹ Therefore, it is important to help older people in pain to be able to access facilities and services that can help them maintain a routine of moderate physical activity within their capability.

Further, it is vital that older people in pain are trained in behaviours and strategies that can reduce persistent pain. Comforting and responsive strategies can be used to help older people maintain or regain a sense of endurance to manage their pain; however, such strategies remain relatively undocumented and are not easily available.⁹²

The provision in the UK of specialist services to manage persistent pain in older people is highly variable and older people are rarely referred to and treated in pain management programmes.⁹³ Pain in older people is not seen as a priority by comparison with cancer care and palliative care, which are offered to older people.⁹⁴ Specialist palliative services are usually better organised, with clearer policies and better funding than those for persistent non-cancer pain.⁹⁵ Pain clinics generate direct health service savings equal to twice their running cost, yet rarely receive the recognition of being treated

as a separate hospital service; moreover, the provision of a facility to address persistent pain is often not defined as a separate service in many areas.⁹⁶

The World Health Organization recommends prompt oral administration of drugs in the following order: nonopioids (aspirin and paracetamol); then, as necessary, mild opioids (codeine); then strong opioids such as morphine. Additional drugs – ‘adjuvants’ – are used depending on the nature of the pain experience. The oral route is the preferred one and should always be considered in the first instance. If morphine is given orally it should be titrated upward in gradually increasing doses until a dose is found that maintains continuous pain relief, while every possible precaution is taken to avoid toxicity. The goal is to keep the patient pain-free at all times. Other interventions, including spinal analgesics, epidural steroids, spinal cord stimulation and nerve blocks, may provide further pain relief if drugs are not wholly effective.^{97, 98, 99}

The effective treatment of pain in older people requires specialised knowledge and training in pain management. Management of pain is a vital factor in people’s ability to cope and live with long-term conditions. Therefore, facilities need to be designated and defined for treating persistent pain in older people, and awareness needs to be raised with regard to specialist pain clinics.¹⁰⁰

Table 5 Ways of managing pain

- ‘I can’t tie shoelaces now, so I’ve just got these slip-ons and I’ve got a long shoehorn. So you do make these adjustments as you go along.’
- ‘I can’t keep my head down to read a book now so I use a music stand. Put my book on a music stand. It works brilliantly.’
- ‘Thinking in advance. I’m planning my life out, pre-empting pain... I have a mattress behind my settee in my front room and I’ll just have to lay that on the floor, in case I can’t get up the stairs.’

- ‘When you are busy, your mind’s active and you’re not worrying about the pain. You can cope with it a lot better.’
- ‘Having to reinvent yourself and then accept that you’ve got to reinvent yourself.’
- ‘Being careful of good days, because you overdo it and it’s very dangerous. That’s why we call them “sodding days”. “Sod it, I’m going to do it. I’ll pay for it later.”’
- ‘Trying to keep that laughter, joy and upbeatness going.’
- ‘You’ve got to think positively. Cope with the bad days, enjoy the good.’
- ‘I think it is always wise to pace myself and approach different activities with a little bit more care.’

Extracts taken from ‘listening events’ and interviews held with older people who suffer pain

Challenging attitudes and beliefs

A lack of knowledge concerning pain in older people, a failure to assess the pain and an underestimation of pain by healthcare professionals and older people themselves all contribute to the unnecessary and unacceptable suffering of older people in pain.¹⁰¹

Attitudes and beliefs of professional care-providers throughout the healthcare system contribute to and affect the outcomes of pain management and patient satisfaction.¹⁰² There is a general acceptance by both older people and healthcare professionals that with increasing age the onset of pain is an inevitable consequence of the normal ageing process.¹⁰³ Increased stoicism in older age and the desire to be a ‘good patient’ – not wanting to cause concern or make an issue of their pain, rather than addressing it – are also common attitudes.¹⁰⁴ Such beliefs and attitudes reduce the usefulness of an ache or pain as a warning indication of disease or injury and potentially result in older people failing to seek any form of treatment and an acceptance that persistent pain is incurable.¹⁰⁵

Such misconceptions and deficient knowledge among individuals responsible for the treatment and care of older people with persistent pain has a negative impact on the treatment. Concerns about the over-use of analgesia (in particular, opioid treatment) for fear it may lead to tolerance, dependence, addiction and unwanted side effects further compromise the treatments provided.¹⁰⁶ Healthcare professionals strongly influence how older people behave and their attitudes and beliefs are frequently mirrored by older people themselves, who often regard the use of analgesia with suspicion and reluctance, many of them harbouring the belief that opioids should be administered only when the pain is 'severe'.¹⁰⁷

Many older people do not seek help at all for a variety of reasons, including negative interactions with healthcare providers and a fear of medical treatment.¹⁰⁸ Many older people feel let down by the health system and believe it views them as being 'past a useful age'; hence, such older persons often feel resentment that leads to a low expectation of the health system and health professionals. Yet, research suggests, older people often value and find it therapeutic to have someone listen to them, understand how they feel and provide information and encouragement regarding their persistent pain.¹⁰⁹ In harmony with this, we found the majority of older people involved in the interviews and discussion groups we conducted were generally pleased to be given the opportunity to recount their experiences.

Additional research is needed to investigate further the multidimensional experience of persistent pain in older people. For example, race and ethnicity are an important factor in influencing what strategies an older person will implement to manage their pain.¹¹⁰ Therefore, efforts are needed to research further and implement effective pain management programmes in diverse communities and settings, and to understand cultural and religious aspects of pain management. Further research should also focus on how both physical and psychological barriers can be managed to ensure adequate provision of pain management for older people.

2 Discussion and recommendations

It is clear from the summary of key literature that the high prevalence and impact of pain on the quality of life and dignity of older people makes pain in older people an important health issue, and one needing immediate attention. It is therefore essential to translate such research on pain assessment and management in older age back into the community setting. With this in mind, we would wish to see four main principles established.

Firstly, **pain is not a normal part of ageing** and must not be tolerated – either by older people themselves or by those responsible for their care. Older people should know that if they want to report their pain, they can do so, and should be reassured they will receive whatever help is possible to cope with and manage it. Older people's confidence in reporting pain is likely to be increased if their reports are listened to and believed, discussions about pain are actively facilitated, and their awareness of current treatments and services is improved.

Secondly, **ageist and discriminatory attitudes toward older people in pain must be challenged and ended**. Such attitudes as 'What do you expect at your age?' are likely to result in avoidable pain and discomfort being left untreated. It is unacceptable and wrong for older people suffering in pain to be left without the appropriate assessment and treatment. Pain relief is a universal human right for all.¹¹¹ A more proactive approach is needed to ensure that the dignity of older people is not threatened by unnecessary pain or discomfort.

Thirdly, **attention should be focused on identifying the physical, psychological and social risk factors relating to persistent pain in older age**. Pain should be treated on an individual basis and in the context of the family and culture familiar to the older person. Hence, help is needed to empower older people who suffer pain to become experts in the self-management and treatment of their long-term conditions.

And finally, **the impact that pain has on the quality of life, and the dignity, of older people must be recognised**. More needs to be done to support older people in pain. The role of the carer is increasing – whether as a result of individual choice or a consequence of policy change. This is illustrated by the introduction of such schemes as the personalisation agenda, Direct Payments, Individual Budgets and Self-directed Support to provide greater flexibility and choice in the care an individual receives and who does the caring. It is therefore vital that high-quality care provided to older people living with painful conditions and that those caring for older people fulfil their duty of care to them.

Recommendations

1 For government and policy-makers

The Department of Health must recognise assessment and treatment of pain in older people as an urgent public health issue and ensure they are an integral part of improving care and services for older people.

- PCTs should include an assessment of pain management services for older people in their joint strategic needs assessments, in order to inform commissioning
- PCTs should encourage GPs and practice nurses to raise their awareness of the effect of pain in older people
- PCTs should commission services which:
 - reflect the breadth of need for pain assessment and management services, including specialist pain services for older people living with persistent pain
 - are accessible through self-referral or referral by friends and family
 - are accessible to older individuals with communication difficulties
 - are properly resourced, with emphasis on increasing the number of pain specialists to meet the demand for more precise assessment and management of pain in older people

- Any future reviews of the National Service Framework for older people should include a standard to address the issue of persistent pain in older people and set out a programme of action to ensure progress is made
- The Government must give greater attention to the issues affecting those caring for older people in pain by funding counselling and support services; pain has no mention in the Government's recent Carer's Strategy
- Understanding dementia and the effect the condition can have on communicating pain and discomfort should be a priority for care home staff, hospital nurses and other health professionals. This was not mentioned in the recent National Dementia Strategy.

2 For regulatory and professional bodies

Pain assessment and management should be integral to the education and training programmes for all health and social care staff working with older people in all care settings.

- The Government should fund an educational campaign targeted at community-based nurses and GPs to raise awareness of pain in older people and highlight the importance of referring cases to specialist pain services where appropriate
- Skills for Care and Skills for Health should include persistent pain in the Older People's National Workforce Competence Framework (2005);¹¹² this should include a component on support and treatment of older people with learning or communication difficulties, or dementia
- The National Occupational Standards should include assessment and management of persistent pain in older people as part of the workforce competences and implement the standard as a basic education and training for social care
- The newly formed Care Quality Commission (CQC) should introduce a standard on pain management in care homes. In addition, it should regulate and monitor the NSF

requirement that older people on four or more repeat medicines receive a medication review at least every six months

- The CQC services used to assess and treat pain in older people should be reviewed to ensure that older people in hospitals, hospices, care homes and people's own homes are not unfairly discriminated against; such services need to be evaluated for their out-of-hours support and improved accordingly
- Specialist training should be provided for community pharmacists and other relevant health professionals on the use of analgesia in older people with co-morbidities
- The NHS Institute for Innovation and Improvement must highlight innovative practice in the management of pain in older people and disseminate advice to healthcare professionals and care-providers.

3 For the NHS and social care agencies

- All health and social care authorities should provide suitable pain management programmes to teach older people about pain, how best to cope with it and how to live a more active life
- Specialist pain services need to be tailored to older people and made more accessible, with access to secondary services included in an agreed care pathway for managing pain in older people
- A standardised pain assessment tool should be implemented and incorporated into regular care planning for older people, with pain identification and assessment to be conducted systematically, including observation and self-report of pain by older people, with relatives and care providers involved where appropriate. Any health or social care assessment of an older person should include asking whether they experience pain. The assessment should recognise that older people may be reluctant to acknowledge and report pain¹¹³

- Current guidance on pain assessment (developed by the British Pain Society, working with the British Geriatrics Society and the Royal College of Physicians) should be implemented by all practitioners in assessing the presence of pain in older people
- Service-specific regulations relating to pain management need to be included in revisions of the Care Homes Regulations 2001
- The CQC should introduce new regulations requiring all care homes to develop a written policy to effectively identify assess and manage pain in older people
- Non-pharmacological interventions should be evaluated by NICE and guidelines developed for referring patients, to ensure that NHS funding is directed to effective treatments
- The Department of Health must ensure the implementation of the Clinical Standards Advisory Group target that requires consultants providing specialist chronic pain services to be contracted for a minimum of three sessions per week for that purpose¹¹⁴
- PCTs should develop satellite clinics in GP practices and health centres to hold regular pain consultation sessions dealing with GP referrals.¹¹⁵

4 For research

More research is needed into the following areas:

- the experience and assessment of pain in older people, particularly those who are cognitively impaired
- the multidimensional experience of pain in older people in diverse communities and cultural settings
- the appropriate and effective use of analgesia in older persons
- how physical and psychological barriers can be managed to ensure adequate provision of pain management is made available to older people

- the needs of the informal care-giver and how they can be supported in providing care for an older person living with pain
- the external environment and assistive technologies that are available and need to be further developed to help older people in pain.

Further advice and support

If you are suffering from pain in older age and would like more information regarding further information and services available to you, please contact the following agencies for advice and support:

Action on Pain

20 Necton Road, Little Dunham,
Norfolk PE32 2DN
Helpline: 0845 603 1593
Email: info@action-on-pain.co.uk
www.action-on-pain.co.uk

Pain Concern

PO Box 13256, Haddington EH41 4YD
Listening Ear Helpline: 01620 822572
Email: info@painconcern.org.uk
www.painconcern.org.uk

Patients Association

PO Box 935, Harrow, Middlesex HA1 3YJ
Helpline: 0845 608 4455
Email: helpline@patients-association.com
www.patients-association.org.uk

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