

Health and wellbeing in care homes The second year of the R&RA campaign

The campaign launched by the Association in July 2008 to raise awareness about the health and wellbeing of care home residents is now in its second year. The importance of the issues raised by the R&RA has been recognised by the Department of Health and the Freemasons' Grand Charity, which have both awarded grants to support the work being undertaken.

After two successful conferences held in the first year, a third conference, based on the theme of dignity in care, was held in July 2009, on this occasion focusing on the key topics of oral health and the management of continence. Professor Jimmy Steele, Chair of the independent review of NHS dental services in England, launched the R&RA's updated publication on oral health, *Keep smiling*, commending the Association for its welcome and timely contribution to this crucial matter for everyone concerned with the quality of life for older people in care homes. Dr Adrian Wagg, consultant geriatrician at University College Hospital London, gave a powerful and moving address on how the preservation of an individual's dignity must always be at the core of managing continence problems.

During this year, surveys have been conducted on the availability of dental services for care home residents and the provision of continence advice by primary care trusts to care homes. R&RA chief executive Gillian Dalley spoke at a recent Royal College of Nursing conference on the continence survey findings. Plans to collaborate with the British Geriatrics Society on a leaflet on the management of continence for care homes are under way. Other leaflets and booklets on health and wellbeing are also being prepared.

There are indications that the importance of the issues around healthcare is being recognised more widely. The decision by the Care Quality Commission to undertake a review of healthcare in care homes is warmly welcomed by the R&RA, which has been involved in some of the preparatory work.



Delegates at the health and wellbeing conference held in July 2009

A National Care Service?

The national consultation on the future shape of social care as set out in the green paper, *Shaping the future of care together*, closed in mid-November. Its main focus has been on how social care will be funded.

Five main options were described, although two were rejected out of hand. The three that have been up for discussion propose variations on a theme of insurance (voluntary or compulsory) with the state contributing a portion to cover the costs of personal care, but with the individual being responsible for accommodation (hotel costs) paid up front or taken from the estate on death.

The green paper also goes on to describe a 'National Care Service' whereby a standard service will be available to people across England in whichever council area they live. Assessment, cost and availability will, it is pledged, be consistent and transparent.

Based on the experience of callers to the R&RA advice line, it is clear that having to pay for costly social care comes as a great shock to many people when they first come into contact with the social care system. They are often bewildered by the complexity of the system for assessing care needs and financial means. They often find it difficult to locate a care home that suits their needs or those of their loved ones and they often know next to nothing about council assessment procedures. They are shocked by the lack of consistency across the country.

It could be argued that almost anything would be better than the current system. However, whether what is being proposed and what system will eventually be chosen will actually meet the complex and varied needs of the country's older population remains to be seen.

R&RA represented at No 10 lunch



R&RA chief executive Gillian Dalley (far right) was one of a small group of representatives of voluntary organisations, all members of the National Council for Voluntary Organisations, who attended a lunch in July at No 10 Downing Street hosted by Chancellor of the Exchequer Alistair Darling and Mrs Darling. Other organisations represented included READ International, Women's Health and Family Services, and King Henry's Walk Community Garden.

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The advice line reports on a perennial problem ...

As ever, how to pay care home fees, as well as the financial obligations of local authorities, are the subject of a substantial number of calls to the advice line. One topic keeps cropping up: relatives being asked to make a contribution to the cost of their loved one's fees.

There has never been an obligation on families to financially support relatives who need (health) care due to illness or disability; and the provision in law which gave local authorities the option of asking husbands or wives to pay towards the (social) care of their spouses has recently been overturned. However, families and partners of care home residents often have little option but to find weekly amounts to pay towards their relative's care home fees. These payments are known as third party top-ups and this is not the way the system is supposed to work.

Third party top-ups are voluntary payments. There is no legal obligation on partners or other family members to pay the difference between the care home fees and what the local authority will pay unless the reason for the top-up is that the resident has chosen a more expensive home than other, suitable, home. What many authorities forget is that the rate the local authority offers towards residents' fees should be enough to pay for appropriate care in a suitable care home without the need for any top-up.

Where the system gets complicated is over the issue of what constitutes 'appropriate care'. For example, we would argue – and Department of Health guidance to local authorities supports us in this view – that, for most people, being close to family and friends is an important part of what makes a suitable home. So, if the nearest care home is more expensive than care homes in other parts of the county, residents or their families should not have to find extra money to pay the difference. The responsibility for meeting the full fees lies with the local authority.

Local authorities are dealing with public money. They have to make sure they get value for money and if they were to agree to pay whatever private care homes asked, fees would rise considerably. But care homes complain that local authorities do not pay enough to cover the costs of providing care. Care homes therefore ask relatives for third party top-ups, raising the rates for people paying their own fees, or they charge for 'extras' on top of the fees.

Third party payments are not a new issue. The R&RA has been giving advice on paying for care for more years than it would like to remember and third party payments are a recurring problem. We would like to see local authorities obliged to give all prospective residents and their relatives access to independent advice before any decision is made about care homes and how the fees are to be met.

... and finds recent guidance on confidentiality may be helpful for relatives

New guidance issued to doctors, describing their responsibilities to maintain patient confidentiality, could prove useful for people who call the advice line with concerns and questions about the healthcare of a resident. The guidance, *Confidentiality* (2009), sets out when and why GPs should consult and share information with relatives. While it emphasises that relatives do not have a general right of access to a resident's medical records, it does clearly say that, for

patients who lack capacity, it is reasonable for GPs to assume that the patient would want those closest to them kept informed unless they indicate otherwise. This, we hope, will help those relatives who feel excluded from decisions being made about their loved ones' care or who complain when they find out about medication or treatment after the event or by accident. The guidance is available from www.gmc-uk.org/guidance

Calls about screening and assessment

Calls on this topic have increased in recent months. Some councils and PCTs increasingly use screening to deny people access to assessment for social care services at home, to residential care or to NHS continuing healthcare funding. The wording of community care law says that councils should assess anyone who appears to be in need of a community care service. The eligibility bar for an assessment is therefore low. Asking for an assessment should be a relatively straightforward process even though it may take a long time to happen.

However, in some cases, people are asked questions – by untrained staff over the phone – that can result in them being turned down for an assessment. Many are not even aware that the process has occurred and so they are not given the right to disagree with the decision. We have heard of people simply being told they are not eligible to be assessed for NHS continuing healthcare without any form of assessment taking place. It would seem that more and more obstacles are being created, blocking access to services that people legitimately have a right to receive.

... and finally

The advice line has received a number of worrying calls about the valuation of jointly owned property. It seems that councils are misinterpreting or ignoring government guidance on how to value property that is jointly owned by the care home resident and someone other than their spouse or partner.

The guidance to councils is clear. Rather than judging the value of the property and splitting it between the owners, the council should value the resident's interest in the property. For example, the value of a half share of a house that cannot be sold is not very much. We would be very interested to hear from anyone in this position.

Chris Ardill,
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chris.ardill@relres.org



The Relatives & Residents Association Advice Line

020 7359 8136

Open 9.30am–4.30pm,
 Monday–Friday

Dear R&RA,

Thank you so much for all the help you gave me, between February and June 2008. In April of that year I contacted my father's MP and my own (at the suggestion of Dad's GP) and within a few days the local authority in the north east of England agreed to pay for Dad to come south, not to my county but to a place still less than 10 miles from me, and chosen because the care homes were better than in my own county.

I would not have held out so long without your support and feel my choice of home was better because of your advice. We were never sure if the decision was made because of the MPs or because we had dug in!

We eventually received a letter from my local social services, which totally ignored our grievances and passed the blame on to Dad's previous local authority.

The procedure was awful, so politicians arriving on our doorstep for the recent elections were there a very long time. Dad died at the beginning of June this year in the general hospital. It had been decided that as he had lived in his present local authority and been registered with a GP there for a year, they should take over his care. Again he was turned down for continuing care and while they were arguing over who should pay and where he should go, he slipped away!

I am so relieved that he was oblivious to the fights and discussions throughout the year plus. But thank you so much for being there and helping us/me.

Anon

Dear R&RA,

My partner's mother seems to be very well looked after at her residential care home in East Anglia ... She has such serious short-term memory loss that just experiencing daily life is enough of an adventure for her. She has her own plant to look after to the extent that she can, which is said to add significant length to people's lives in care homes, and she gets lots of visitors ...

The staff have always seemed approachable and friendly. The premises and residents look clean and well cared for. The residents seem to be women of a similar age and ethnicity to my partner's mother, not inclined to chattiness among themselves. She always seems cheerful, as she always has seemed, and comfortable.

Anon

The Relatives & Residents Association (Essex)

The Essex branch celebrated its first anniversary in October – a full year since our official launch. Although we haven't had a party, we are planning to organise an event in spring 2010 at which we can meet all our members, friends and stakeholders and have a celebration of all that has been achieved so far. We are also keen to get their ideas about the services we have in place and the path we should be taking.

Perhaps the most significant development since our article in the previous newsletter has been the appointment of our development officer, Debbie Tanner. We were delighted to receive the application from Debbie, who has been an enthusiastic supporter ever since we were first in touch with her. She came to us from a post as a day centre manager with a small, but very active, voluntary organisation and has a lifetime's experience of promoting the wellbeing of older people and their families.

Debbie has been working very hard on two projects. One is to start establishing a network of local representatives across the wide area we cover. We are hoping these people will help us to spread the word about our services as widely as possible in their own areas and also to become the focus for groups of volunteers who will be able, with good training and support, to offer personal help where it is needed. They will not be taking the place of the advice and help line, of course, but they will be able to supplement the great work that Chris Ardill, the advice line manager at the London office of the R&RA, is doing. They will also be able to feed back information to us and to him about local issues.

The aim of the other project is to build partnerships with as wide a range of different groups as possible. Any organisation that may be in touch with people who might need our help is a possible partner. We are particularly concerned about the people who may have the advice and help line number, but still hesitate to ring, for any one of many different reasons. We hope that our volunteers and partners will be able to dispel their doubts and support them in the most appropriate way to get the help they need. Organisations of people from minority ethnic groups will be amongst the potential partners with whom we would most like to make links.

It is clear to us that there is as much work that needs to be done as we can take on



Development officer Debbie Tanner with Tom Cooper at an event held by the Tendring and Colchester Minority Ethnic Partnership in summer 2009

and a great deal more! We have been lucky enough to secure some extra help for Debbie in the form of Jill Jimson, who will be taking on some work in support of these projects on a consultancy basis. Our main sponsor, Essex County Council, is also supporting us with some time from our project support officer, Nikki Donovan, who, like all of us in the Essex branch, is 'hooked' on the R&RA and proving to be an invaluable colleague in all kinds of ways.

To take us into our second year and beyond, we now have the nucleus of a very able management board, chaired by Brian Mister, who has a wealth of experience and wisdom to offer us. Our excellent webmaster and IT guru, Chris Harvey, has taken on the role of vice chairman. The third pillar of our voluntary committee, alongside the ex officio members, is Tom Cooper, the staunchest of our friends and allies from the very beginning and the author and star of the video (there is a link on the Home Page of our website, www.relressex.org).

We are delighted to have gathered such a strong team locally and we continue to be profoundly grateful for the continuing support and friendship of the staff and volunteers in London. Our particular thanks go to Chris Ardill for his superb work on the advice and help line, which is the foundation of our work and success.

**Janet Russell, Joint Project Manager,
Essex County Council**
Tel 01621 868984, info@relressex.org

End of life care: a member's point of view

We thought readers would like to share the following article, which a member sent to us.

Choosing a care home can feel like a trying, agonising step whenever the time comes. My own experience had no warning – an emergency hospital admission led to my dad being diagnosed with cancer which had spread to his bones. First there was the shock of learning his illness was advanced, then the realisation that he couldn't return home since he was paralysed and needed constant nursing care.

An efficient social worker gave out a list of local nursing homes – the number was limited as the home had to be registered for terminal illness care. The move to discharge from a community hospital into self-funding nursing care felt rushed. It left no time for adjustment. There is the sense that an NHS hospital (with targets) wants to get rid of the patient (whom they have given up on). The words 'nursing home' are perhaps the most feared, by the cared-for person and their family alike.

The Care Quality Commission ratings seemed a good place to start. We were fortunate to find a three star nursing home which could take my dad immediately. He was given a lovely room with a patio window and his basic care needs were well met throughout his stay. However, the style of care, his private nature and impact of his cancer meant his specific individual needs were harder to fulfil.

Providing and receiving care became difficult. Carers turned my dad though this was in fact overriding his wishes. He already had pressure sores but did not want to be moved, especially at night. This routine continued as his skin was at risk of infection or deeper sores. He became depressed when he realised nothing more could be done to return him to his previous active life. The home's staff tried to get my dad up for meals by using a hoist but he was too weak and all movement triggered pain.

The specialist palliative care input, from the local hospice and from the PCT care home in-reach team, was excellent; they visited frequently during weekdays. But my dad's pain was severe and complex and he needed admission to a hospice for expert assessment. He died a week later, but I was relieved his pain was at last under control.

If your relative needs to go into a care home due to advanced cancer, talk to the matron about how they improve quality of life. Remember you can visit care homes without giving notice. It helps to know what partnership working there is with hospices, GPs and community nursing services. Palliative care considers physical, emotional, social and spiritual needs so that the time left is the best possible. However, someone nearing the end of life may be confined to a bed or single room. There is a withdrawal from usual interests and the outside world, energy fades and the individual emotionally prepares for death.

Good practice in care homes is to employ activities therapists bringing stimulating ideas into the lives of residents. But my dad was bed-bound and going into the garden or even using a wheelchair weren't options, much as he wanted them. The majority of care home residents would appear to have a diagnosis of dementia – my dad's mental agility made it harder to accept his new situation. But nursing homes may bring in complementary therapies such as aromatherapy, pet therapy, massage and reflexology. These treatments give a pleasant experience without being too physically draining. Relaxation techniques can help with pain control. If well enough, a resident may also be able to attend day care at a local hospice.

My dad was encouraged to eat but there came a point where leaving sandwiches in front of him felt unhelpful. He lost his appetite, though supplement drinks of one variety seemed to sustain him. My dad felt it important not to have the radio left on and not to be weighed (though care homes tend to do this monthly for all residents). He was given morphine 30 minutes before care to try to help with the pain on moving. Choice of clothing was personal though he was dependent on carers for changes. As his daughter I wanted for him to have a sense of managed pain above all; that was more important than any conversation with us or being able to get through meals.

Advance care planning was used in my dad's care; the question of resuscitation (should he lose consciousness) had to be explained. The issue is an emotive one and another part of facing up to death. I wanted to know all I could about my dad's illness and care, whereas my mum felt that bad news would only worry her and that she would be better facing things as they happened. Both

approaches are valid: health workers and care home staff should respect them equally.

Advocacy does have a place where the resident feels no benefit from medication or wants changes to the care plan. Conversations with staff can reinforce what your relative wants and also make your own feelings known. But at times I did worry I could offend staff by advocating for my dad's wishes. Palliative care is to support both the sufferer and family. If your loved one's condition has deteriorated you want to know straight away and spend as much time with them as possible. Staff should answer questions and be empathic to feelings, distress and concerns.

Rapport with staff is important – for both residents and relatives. Trust needs to be maintained though this can be hard if the older person becomes suspicious, for instance thinking water is poisoned or no one cares. Staffing levels should be above a minimum; nights can be the most difficult time for someone who's dying, yet the night shift has a much reduced staff number.

NHS continuing care covers the full costs of care where your relative has a severe illness such as advanced cancer. There is also a fast-track for the final stages of terminal illness. Your local PCT has responsibility for this. A person's eligibility depends on whether their needs are classed as primarily health based rather than for personal or social care.

I returned to the care home to clear out my dad's room two days after his death. It looked the same as when I last visited him except the special pressure-relieving mattress had been removed. It felt sad to go there with my dad missing and to have to take all his belongings, thereby making way for the next resident. I kept his sweater afterwards but discarded toiletries, leaving dressings and first aid. He had never personalised his room with photos or reminders of his life. The physical remains of those final few months were pyjamas, hospital dressing gown, drinking straws and boxes of tissues we had to take in for him.

Most care homes do not have bereavement support services so make sure you contact organisations such as Cruse, local counselling agencies and your GP if you find you struggle in the event of your loved one's death.

Anon

EoLC project Involving volunteers

It has been estimated that one in four people over the age of 85 will move into a care home at some point before they die and it is there that around one in five of all deaths takes place. Thus for many older people, the likelihood of dying in residential care is a strong possibility. Significantly, many care home residents have neither kith nor kin to support them as they come to the end of their lives.

It is therefore crucial that homes themselves fully recognise their responsibilities and make every effort to train staff and managers in end of life care accordingly. While this means having the right policies and procedures in place, it also means ensuring that the individuality and personhood of every resident is actively recognised and placed at the centre of care.

Care homes need to think carefully about the place of death within the general life of the home: what is the philosophy underpinning their handling of death, especially in relation to the wellbeing of other residents? Death is a not unusual occurrence in residential care. It should not be hidden away, but neither should it dominate the overall atmosphere of a home negatively.

Care of people when they are dying must be an extension of care when they are living. It starts when a person first comes into care, with thorough care planning, and talking sensitively with residents about their needs, fears and expectations (and re-visiting this from time to time). It means responding to them with reassurance and compassion, involving relatives – if the resident wants them to be involved – and providing special support where there are no relatives. Part of this might mean involving volunteers.

One of the R&RA's current projects, funded by the NHS End of Life Care programme and reported on in the previous newsletter, is to explore the possible role of volunteers. The project officer responsible for the work, Kate Durrant, is currently recruiting individuals who are interested in becoming volunteers on the project. It involves building links with local care homes and befriending some of their most frail residents. So far three care homes have agreed to participate in the project and a number of potential volunteers are preparing to become involved.

For further information, contact Kate Durrant on kate.durrant@relres.org

Journeying in hope The work of the Irish Chaplaincy in Britain

'It's great to have a visit from somebody in the afternoon. It breaks the silence of here.'

So speaks one of the older Irish residents of a care home in south west London after a visit by one of our outreach workers from the Older Person's Project of the Irish Chaplaincy in Britain (ICB).

The project supports and cares for the most vulnerable and isolated of older Irish people in London, by providing a culturally sensitive visiting service that reaches out to older Irish people in their homes, as well as in care homes and in hospitals, offering emotional, spiritual and practical support irrespective of beliefs or attitude to the Church.

These older Irish are members of that generation of Irish migrants who came to Britain in huge numbers in the 1950s and 1960s. Between 1951 and 1961 alone, over 500,000 migrants left Ireland to come to Britain in search of work and new opportunities. To respond to this huge exodus the Irish Chaplaincy was set up in 1957 to seek out and care for Irish people arriving in the UK in search of a new life. The work that began with this generation continues today through the Older Person's Project. Today there are over 44,000 older Irish people in London alone and there is no other ethnic group in London with a higher age profile.

Our staff team and volunteers work across London, responding to referrals from statutory and non-statutory agencies as well as from individuals themselves or their families and friends.

Our mission is always to 'journey in hope' with the older people, assuring them that they are valued and important and that their lives still have worth and meaning. We travel alongside them, whatever their circumstances may be, nurturing and encouraging them as we go and listening to and valuing their life stories. This is most important as people reach the end of their lives and we support many older people at this time, especially those in care homes and hospitals who have few if any other visitors.

As well as visiting older people and building up relationships with them, our work often includes making contact with older people's relatives and friends on their behalf, whom they may have lost touch with, and we have been able to help families make contact with each other again, sometimes after decades

of separation. We have also facilitated the return to Ireland of several lonely and isolated older Irish, so they can settle back in the country they left so many years before, with family and friends close by.

We also support and encourage older people's families, who may be worried and concerned about their loved one, especially when they have to go into hospital or into a care home. We work closely too with other agencies and organisations to help improve the lives of older Irish people, to ensure they have the benefits and services they are entitled to and are treated with the dignity and respect they deserve.

The chaplaincy organises a range of regular events from tea dances to activities in care homes to ensure that the older people have every opportunity to meet with other people of many different ages, to enjoy themselves and to start to feel reconnected with people and the community around them.

We could not do what we do without the wonderful help of our volunteers of all ages. If you would like to spend some time in visiting older Irish people, fundraising or working on our events and publicity, please do get in touch.

To find out more about the work of the Older Person's Project please contact Paul Raymond at the Irish Chaplaincy in Britain, 50-52 Camden Square, London NW1 9XB, tel: 020 7482 3274, or email paul.raymond@irishchaplaincy.org.uk or visit our website at www.irishchaplaincy.org.uk

Paul Raymond, Manager, Older Person's Project, Irish Chaplaincy in Britain



Tom, an ICB client, on his return to live in Ireland in August 2009 where he was reunited with his family after 25 years

Continence: the key to wellbeing

The R&RA health and wellbeing conference held in July 2009 considered the way in which the management of continence plays such a big part in maintaining an individual's sense of identity and self-esteem.

As Dr Adrian Wagg said in his presentation, 'Not being able to control the body concerning elimination makes people feel unclean, with the body being unrecognisable or shameful because of the way it behaves, looks or smells ... What better indicator of private and dignified care is there than that involved in toileting and continence care?'



Dr Adrian Wagg speaking at the conference

This view underpins the effort that the R&RA has put in during the past year to exploring the availability of continence advice to care homes across England. Lynda Finn, a volunteer, wrote to all 152 PCTs and care trusts in the country asking them about the continence services they provided to care homes in their local area. After a considerable amount of chasing up, 103 (67%) of them replied. The content of their replies varied considerably. Only about a third said they were in regular contact with all the care homes within their catchment areas. Others replied that they were in contact with around three-quarters but others said they were only in contact when a care home contacted them. A few said they did not keep records of contacts.

They also reported on how much training they provided to local care home staff. Most said they provide rolling programmes of training that is available, mostly free of charge, to care homes. Many PCTs registered their concern about the low skill levels of care staff in managing continence. In the light of this concern, it is particularly worrying that most respondents also reported high cancellation and non-attendance rates, even when the training programme was being offered within the

care home. Problems of high staff turnover and the reluctance of home managers to release staff for training were cited as reasons for this.

Calls to the R&RA advice line confirm the seriousness of the findings from the survey. The poor continence management that some residents experience is manifestly a cause for concern. Callers describe how their loved ones can be left in wet and soiled pads and/or beds. Stories are told of residents being put in pads so that staff can have a quiet night. During the daytime residents have been told to use a pad rather than call to be taken to the toilet. In other cases, they have been rationed to a specific number of pads per day. None of these practices is acceptable. It is essential that care homes take up opportunities for training that local PCT continence advisers can provide to ensure that all staff – managers, nurses, care assistants – are regularly updated on best practice.

Further analysis of the survey responses is under way and the results will be made available in due course.

The R&RA is grateful to the Department of Health and the Freemasons' Grand Charity for the support they are providing to the R&RA health and wellbeing work.

Dental care for older people

One of the concerns frequently expressed by callers to the R&RA advice line is about the dental care and oral health of residents in care homes. This has prompted the Association to revise, update and re-issue its highly regarded booklet on the subject. Now entitled *Keep smiling: dental care and oral health for older people in care homes*, this 24-page document provides a concise and practical guide. It helps care staff address the topic of dental care, and assists relatives in knowing what sorts of questions they should ask. It forms an integral part of the R&RA's health and wellbeing campaign.

Maintaining oral health is now increasingly being viewed as being a key part of a whole body approach. Residents in care homes often face difficulties with maintaining dental hygiene. Brushing teeth and keeping

dentures clean can be problematic and care staff may not have the knowledge necessary to assist residents. *Keep smiling* has advice on dental hygiene with a checklist for care staff and an assessment form for use on admission to a care home. In addition, it points out the patchiness of access to treatment. The community dental service in each PCT is responsible for providing dental treatment to those who cannot access mainstream dental services. Carers and care home managers need to be more aware of the availability of these services and refer residents to them. Residents of care homes are fully entitled to all NHS services just as if they were still living in their own home.



The publication was launched in July 2009 at the R&RA conference on health and wellbeing by Professor Jimmy Steele, Chair of the independent review of NHS dental services in England. He writes: '*Keep smiling* offers a common-sense approach for those charged with looking after the oral health of older people in care homes. It is a big step forward.' The booklet is receiving good reviews and selling well. It is recommended by the British Society of Gerodontology, whose aim is to protect, maintain and improve the oral health of older people.

Keep smiling can be purchased through the R&RA website (www.relres.org) or by phoning 020 7359 8148. Special prices are available on orders for multiple copies; for further information contact the R&RA.



The R&RA's health and wellbeing logo

Making a positive choice ...

Over twenty years ago, *Residential care: a positive choice*, commonly known as the Wagner report, first appeared. This was the outcome of an independent review of residential care set up by the then Conservative government. The Social Care Association, a body of individuals and organisations in the field, had become concerned that residential care was under unjustified attack, and could benefit from the injection of some facts to counter this, and so they lobbied for the review to take place.

Although so much has changed since then – the legislation, the standards homes are expected to meet, and the expectations that families have for their loved ones moving to a home – the sense of being under siege has nevertheless continued. Newspapers launch campaigns apparently aimed at upholding older people's dignity by carrying alarming and alarmist stories. Broadcasters are also keen to identify and expose weaknesses in the system and the impact these can have on the lives of vulnerable people. The R&RA shares this concern to expose deficiencies, albeit without destabilising homes.

The Residential Forum was established to promote the messages contained in the original report and has produced a number of important publications since its launch in the mid-1990s. *Residential care: a positive future* follows in that tradition. Terry Philpot, a former editor of *Community care* with a longstanding interest in care issues, edits the book. He has done a good job of marshalling a very broad range of contributors to address some key issues.

One can dip in and out of the book with ease. If the reader needs a few more facts to counter prejudice, they are here; if the same reader wants to reflect on how well homes are managing to enable people to live a good life, there are equally accessible and up-to-date commentaries on good and bad practice.

I have spoken to many relatives of older people living in care homes who chide themselves for having too little 'quality time' with their relative, but plenty of time to worry about care practices – or their own ignorance. I wouldn't hesitate to recommend this book to someone with no prior knowledge of the care sector as a way of furthering their own understanding of the challenges that managers and staff face in providing a positive alternative to living a so-called independent life.

... and understanding more about homes

Good care doesn't just happen any more than poor care is the product of one or two 'bad apples'. *Understanding care homes: a research and development perspective* brings together a collection of papers from a range of initiatives aimed at influencing policy and practice in homes.

The book is arranged in a logical order with a series of contributions focused on 'The individual resident', then 'The organisation', and finally 'Beyond care: the wider perspective'.

While it is a heavily referenced book that the non-professional reader may shy away from, there is much here to interest people working in and around care homes in a variety of roles. Readers of this newsletter may find the chapter on 'Friends of Care Home' groups especially interesting, providing them with the inspiration to consider doing something in a home with which they are connected.

If care homes are to remain a positive choice, those running them need to make use of the findings of research so as not to be left behind in a slot marked 'the past'. This book is as good a place as any to begin the quest for more positive understanding of how care homes operate, how they can change – and above all how they should go about meeting the needs of the people who live in them.

Terry Philpot (editor), *Residential care: a positive future*, 2008, ISBN 978-1-900909-06-8, 184 pages, paperback, £10.00. Published by Residential Forum (www.residentialforum.com)

Katharine Froggatt, Sue Davies and Julienne Meyer (editors), *Understanding care homes: a research and development perspective*, 2008, ISBN 978-1-84310-553-4, 264 pages, paperback, £19.99. Published by Jessica Kingsley Publishers (www.jkp.com)

Reviewed by Les Bright, R&RA adviser



The power of personal stories

Telling tales about dementia: experiences of caring is a book of stories about real relationships touched by dementia. For over two decades I have worked in charities raising awareness of the experiences of family carers. When I started out, my heart was captured by a similar book (*Caring: experiences of looking after disabled relatives*, edited by Anna Briggs and Judith Oliver, 1985). Story-telling is a compelling way of shedding light on difficult situations. No two families are the same and it is impossible to generalise about the impact on relationships of a condition like dementia. Reading about individuals, however, offers an insight into the changes dementia can bring.

A strength of this book is the variety of situations and relationships it covers. There are families from different cultures as well as gay and lesbian carers, who help us see some of the special challenges for carers from minority groups. There are a disproportionate number of carers looking after people of working age with dementia, but this is helpful as the situation of younger people warrants greater attention and awareness.

Photographs break up the text and bring the stories to life, adding to the vivid impression that the reader is being invited into the carer's home to meet the person for whom they are caring. It is a balanced account: some carers received poor treatment from their local services, and are justifiably angry, but others were happy with the support they were offered. The book does not come across as a campaigning tool with a political agenda, it simply presents the stories and allows the reader to reach their own conclusion.

This compilation is highly readable although the stories can be very sad. It is helpful for people with a relative with dementia, enabling them to see they are not alone. My hope is, however, that it will also be read by professionals who come into contact with families; it would be a fitting reward for their courage and honesty, if the carers who contributed were able to see it positively influencing the experiences of other carers.

Lucy Whitman (editor), *Telling tales about dementia: experiences of caring*, 2009, ISBN 978-1-84310-941-9, 224 pages, paperback, £14.99. Published by Jessica Kingsley Publishers (www.jkp.com)

Reviewed by Julia Burton-Jones, freelance care home consultant

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The R&RA team – (clockwise from top left) Colin Hutchens, Alison Clarke, Gerry McMullan, Chris Ardill, Gillian Dalley and Joy McCarthy – sends season's greetings to all readers of the newsletter

Gillian Dalley, R&RA chief executive for five years, and Colin Hutchens, R&RA volunteer for six years and editor of the newsletter, are both leaving the Association shortly – Colin at the end of November and Gillian at the end of December. Both would like to thank everyone for their support and contribution over the years.

Helping out at the R&RA



This issue's 'Helping out at the R&RA' corner features Melanie Robinson, who writes:

'I am very happy to be maintaining the R&RA website. The charity does a great job for vulnerable older people and their relatives and it's a privilege to help out in some small way.

Kamal Jalalian, the previous web developer, showed me the ropes and now it's all up to me! My previous IT experience has been as a technician so website maintenance is a whole new field. It's great to be learning new skills.

Maybe a few changes to the website will be introduced in the near future, so please watch this space!

The R&RA is always looking for volunteers to help in the office. Please ring 020 7359 8148 or email info@relres.org for further details.

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