

The Relatives &  
Residents Association



For Quality of Life of  
Older People in Care

Annual Review 2009

Speaking up

Advice

Health & wellbeing

Working together

Speaking out

## Speaking up

for relatives and residents in care homes

The R&RA is a small charity. But it is not afraid to speak up on behalf of its members and the people who call for advice at what is often a critical turning point in their lives. And being small can bring benefits. There is not a great distance between the staff who talk to residents and relatives on the advice line, at carers' groups or in care homes, and the staff who talk, on the R&RA's behalf, to policy makers, politicians, academics and the media. Often, in fact, they are the same people. So when the R&RA speaks up about the difficulties faced by the families of self-funders in securing their rights to assessment, or the worries many relatives feel about making a complaint about the care their loved one is receiving, they are doing so with the experience of our callers in the fore-front of their mind.

### **What has the R&RA spoken up about this year? How have we done it? What difference is it making?**

Through conferences, research and publications we have campaigned to give authoritative and practical information on sensitive matters crucial to the health and wellbeing of vulnerable people: continence, dental health and care at the end of people's life. Research has led to publications exposing inequalities in access to funding and assessment and what constitutes 'adequate' care in inspection reports. For those isolated people in care homes with no relatives or friends to represent them, who will speak up for them? The R&RA is working on it and will report in 2010.

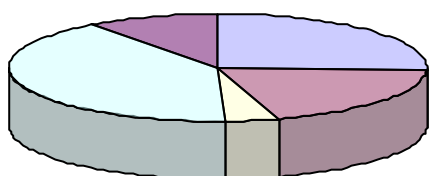
The R&RA speaks with an independent voice to support the needs and rights of residents and relatives when a home has to close, with a practical voice to help busy staff improve their practice, and with a reassuring and knowledgeable voice to whoever contacts its Advice Line.

As the R&RA approaches its 18<sup>th</sup> birthday it's thinking about its future. The Advice Line remains at the heart of the R&RA's work and has become an inspiration and mentor to others wanting to set up a localised support service. New partnerships are now opening up to support extension of this service and we hope more will follow. This is a service so well respected that other charities for older people refer their callers to it.

As demand for our services grows, as the Big Care Debate on future funding gathers momentum, as changes in regulation and handling complaints come into force, we will welcome the support and the views of our members on the work we are doing. We look forward to continuing to speak up on your behalf.

## Advice Line

**Subjects raised on the advice line**



- Admission 25%
- Care Standards 19%
- Management and daily life 4%
- Legal and Financial 39%
- Human Rights 10%

In a year of credit crunch, cuts and constraints, it was no surprise to find financial and legal questions dominating the advice line. “Am I really liable for the top-up fees the local authority is demanding?” “Will we have to sell our home to pay for my husband’s care? What happens if there is no buyer?”

The implications of the Mental Capacity Act and new guidance on medical confidentiality raised complex questions of interpretation, as do so many other issues when a range of services share or overlap in providing care. The advice line is there, Monday to Friday, 9.30 – 4.30, to help.

Key areas causing concern to callers are now the subject of a growing series of leaflets under the title, *Living in a care home*, specially written for relatives and available on the R&RA website. They will help people with little experience of care homes to make informed judgements about what is good, bad or indifferent practice. As well as giving relatives confidence and useful information they should raise expectations and indirectly encourage improving practice in care homes.

### Reaching more people

Over 3,000 people call us every year for help and advice but we would like to reach many more. One of the ways that we can be of most help is at a very specific point in people’s lives – when they’re trying to find and pay for long term care for themselves or a loved one – and one of our ongoing challenges is to find ways to reach them. We are assessing the results of our pilot Partnership Advice Line with five not-for-profit care home providers to see how associated services might be developed. We know that most people who move into care homes have some contact with their local authorities so this year the R&RA began to develop formal links with local councils who would promote access to the R&RA advice line as part of an enhanced service to its residents.

The service, actively supported by Essex County Council, has become well embedded in the area. It has its own dedicated development worker and steering group and forms a model that other local authorities are considering with interest.

## Speaking out

Called upon to speak to the media and policy makers, the R&RA has given oral evidence and written briefings to parliamentary committees, has spoken out on radio and TV and in articles in the specialist and national press.

*“If you have been affected by any of the issues....”* the words following so many TV and radio exposés of elderly care matters, have led many people to the R&RA as a source of information and support.

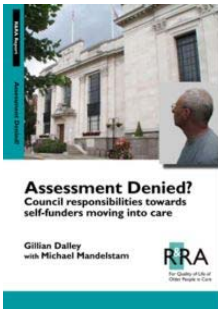
We drew attention to the plight of care home residents with dementia in evidence to the All Party Parliamentary Group on Dementia and to the vulnerability of care home residents to abuse of their human rights to the All-Party Parliamentary Human Rights Group, as part of long-running campaigns in these two areas. We were delighted to see the publication of the government’s National Dementia Strategy (with the promise of similar strategies in Wales, Scotland and Northern Ireland), although so much still remains to be done to improve dementia care in care homes. We were also pleased that Parliament extended through a provision in the Health and Social Care Act 2008 the protection of the Human Rights Act to people living in privately run care homes. Previously this had applied only to the relatively small number living in state-owned homes. However, this change still falls short of what we would like: it is restricted to residents whose fees are funded by the state or where their contract is arranged by the state. It does not usually include people arranging and funding their own care (so-called self-funders). We shall be campaigning vigorously to extend human rights protection to all older people in care homes.

### **Let’s talk about it**

Leading and participating in conferences, workshops and focus groups the R&RA has been a sought after contributor to university research projects. University consortia, led by Brunel University into financial elder abuse, by the University of Surrey through its SomnIA sleep in ageing research and by Cardiff and Bangor Universities as part of the PEACH initiative to improve care home practice, all value the direct connection with experience which R&RA offers.

### **Let’s read about it**

An important outcome of much of the R&RA’s project work is a well researched, informative and reliable publication. Successful and authoritative publications have also resulted from work prompted by calls to the Advice Line. Inconsistencies and inequalities in interpretation of guidance and regulation have been revealed as callers have described their experience and the advice or demands they have received from different authorities and in different areas. This has led to hard-hitting publications which have demanded attention and continue to do so as the national care system and its funding comes under scrutiny in the light of impending change.



**Assessment denied? Council responsibilities towards self-funders moving into care**

We have drawn attention to serious inequalities in councils' provision of a full examination of their needs to people who may have to pay for their own care. At a point when they are considering their options, this book sets out clearly what they have a right to expect when they seek help from the local authority.

**Keep Smiling Dental care and oral health for older people in care homes - a guide for staff, residents and relatives**

This practical guide was published in July 2009 as part of the Health & Wellbeing in Care Homes campaign. The R&RA has long campaigned for the importance of oral health and has given practical guidance on looking after it. Maintaining healthy teeth and gums may be easy to overlook among a population with multiple and complicated healthcare needs, but it is crucial to residents' nutrition, wellbeing and quality of life.



**Inspection in Action - Making Inspection Work**

*A survey of the inspection reports of 100 care homes given one star and rated 'adequate' by the Commission for Social Care Inspection*

Good inspection is key to ensuring good quality care. As the Care Quality Commission was in the process of taking over the responsibilities of the CSCI, this survey represents the R&RA staff team's urgent response, released in May 2009. Their findings revealed serious discrepancies in inspectors' ratings and unacceptable tolerance of poor practice. With the assurance that the CQC has recognized the problem

the R&RA is keeping this work under review.

**The R&RA Newsletter**

Lively and informative, the newsletter has offered regular updates on all R&RA activities and featured articles, letters, book reviews and poems, with contributions from so many with an interest in and enthusiasm for the Association. We particularly encourage input from our members.

[www.relres.org](http://www.relres.org)

The latest news, resources for download, comment and how to get in touch.



## Improving practice

The problems that are difficult, the subjects that are too sensitive to talk about, these are where the R&RA will help, will face the issue with you and provide well-informed, practical guidance and solutions.

The R&RA's own campaign for **health and wellbeing in care homes** has had the support of the Department of Health and the Freemasons Grand Charity in its work towards greater understanding and improvements in such areas as continence matters and dental care, medication and dementia care.

The R&RA's campaign started from the recognition of a very simple principle: that residents of care homes for older people have exactly the same rights to general and specialist healthcare as everyone else and yet, too often in practice, they are not able to exercise them. The R&RA held two well attended conferences and issued associated publications, warmly welcomed for the opportunity they gave to look in detail at how good practice can make such a positive difference to quality of life.

The theme of health and wellbeing also underpins other R&RA projects during the year, which operated with a range of funding support.

The R&RA was delighted to be selected by the NHS to lead the aspect of the Department of Health's major initiative on **End of Life Care** which specifically deals with support in care homes, to ensure that care of people when they are dying is an extension of their care when they are living. The project helps with such issues as sensitivity to the involvement – or not – of relatives, and the special support they need when they are alone.

It has long been a concern of the R&RA that so many elderly residents in care homes have no-one to speak up for them. A study of the numbers of **Isolated People in Care Homes**, without relatives or friends to visit them, is the subject of one of our ongoing projects supported by the Department of Health. We aim to identify ways of developing advocacy, befriending and local support for people alone in this way.

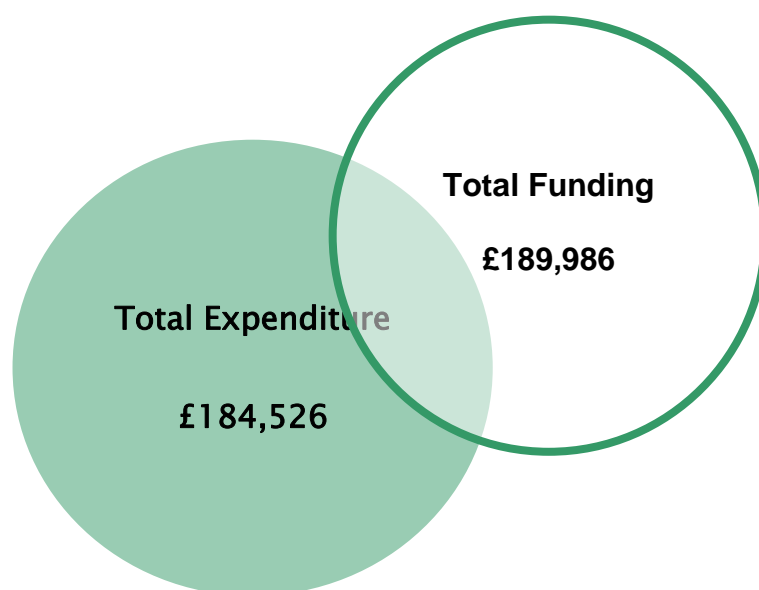
**Thinking about improving practice** is the R&RA's title for its work in association with Action on Elder Abuse, funded by Comic Relief. The project earlier identified as 'prevention of abuse', has produced upbeat, practical, succinct guidance aimed at supporting and informing care staff. It should indeed encourage positive thinking towards improving practice. Presented as 'Briefings' on the R&RA website further topics are planned.

Residents and their relatives who have been told that their home is to close may be angry, bewildered and scared. Independent advice on how closure should be handled and what rights and options they have is vital. The R&RA's personal involvement and its paper, **Moving on – with care**, puts protection of each resident's interests at the forefront when such action is proposed or taken.

## Funding

<b>Incoming resources from generating funds</b>	£
Voluntary income	72,594
Investment income	3,064
Other	334
Incoming resources from charitable activity	113,994
<b>Total</b>	<b>£189,986</b>

<b>Resources expended</b>	
Costs of generating funds	3,221
Charitable activities	174,084
Governance costs	7,221
<b>Total</b>	<b>£184,526</b>



It has been a difficult year, but there was a surplus of income over expenditure of £5,460, which was satisfactory. At 31<sup>st</sup> March 2009 there was £68,378 to be carried forward for the completion of projects (£76,297 in 2008). We have been grateful for the continued generous support of our charitable funders and are pleased to see a growth in contract work. We specially appreciate the contribution made by our members.

Copies of the full accounts are available from R&RA on request.

## Speaking of the future

On 31<sup>st</sup> March 1993, Dorothy White's brainchild The Relatives Association was born "to help relatives and friends to work with Homes to ensure the highest possible quality of life for all older residents". As a five year old, recognizing that the focus of relatives and friends was always the best interests of residents, it became The Relatives & Residents Association. Now in its eighteenth year, with its collaborators, its funders, its friends and its members who have supported its work for so long, the R&RA will be looking carefully at the future direction it should take.

### **To 2009**

From 2004 to December 2009, Dr Gillian Dalley has led a strong and committed team of staff and volunteers, her own experience and the activity she has developed adding a dimension of academic authority to much of its work. We are grateful to her and to Office Manager Joy McCarthy, to Dominic Regan and to volunteers Lynda Finn, Colin Hutchens, Kamal Jalalian, and Gerry McMullan, for the important contribution they have made. They leave the Association with a solid foundation on which to build and they will be much missed.

### **From 2010**

As the R&RA seeks new leadership and consensus on its vision for the future, Chair Judy Downey combines this responsibility with the role of Acting Chief Executive. Under Chris Ardill's management the Advice Line continues to grow, invigorated by its Essex and Hertfordshire links. Alison Clarke supports this and takes forward Health & Wellbeing project work, while Professional Adviser Les Bright, specialist staff, including Kate Durrant and Debbie Tanner, and volunteers including Melanie Robinson managing the website, are valued contributors to the team.

### **Working Together**

Being independent does not mean being alone. Keeping an independent and distinct voice that can challenge, provoke and insist on higher standards, the R&RA attracts the attention, the funding support and the active collaboration of government departments, charitable foundations, academic institutions and a range of organisations providing services for older people. It continues to extend its network of professional experts and advisers to ensure that the advice and information it gives and the good practice it recommends is accurate, useful and up to date.

None of this is possible without the support of our members, our grant givers and our project partners and we thank everyone who has been, and who will be making the R&RA a force to reckon with in speaking up and speaking out for older people, their families, carers and friends.

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