At the Leveson Centre

- we are a focus for interdisciplinary study of ageing, spirituality and social policy
- we establish and make accessible information about these subjects
- we contribute to best practice through publications, conferences, public lectures and seminars
- we network with other agencies, projects and individuals
- we are developing an understanding of spirituality as lived by older people and support them to express their spiritual awareness - and learn from them
- we support and enable older people to influence policy makers, professionals, carers and churches
- we identify, and disseminate distinctive contributions that Christian churches can make to the development of social policy and see how we may bridge gaps between theory and practice
- we explore multi-cultural aspects of ageing
- we sponsor or co-ordinate research projects

For further information about the work of the Centre, please contact us using OUR NEW CONTACT DETAILS

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Registered Charity No 213618
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Editorial

Working with Older People: A Resource Directory for Churches

It is a paradox of modern life that despite the significant increase in speedy local, national and international communication it isn’t always straightforward to know where to turn for information, support or advice. The proliferation of words and information hasn’t always enabled us to reach a deeper sense of understanding or wisdom.

At a recent party here in the Leveson Centre someone challenged me to declare what my vision was for the Centre. I talked with some pride about the quality of our conferences and the slowly expanding list of publications. My enquirer pressed me to articulate what my vision for the centre was and what I hoped we might be able to achieve in two or three year’s time.

It is our hope in the Centre that we can work as partners with others in challenging the church both to think and to act differently in relation to older people. We hope that churches might value and affirm the many good things that are happening amongst older people across the country. We hope that older people might be given a voice and be made visible. We hope that the churches might see older people as an enormous spiritual, political and human resource for mission and ministry.

This ambitious vision will require resource, energy and a preparedness to challenge many of the prevalent attitudes both in society and church about age and ageing. A first step in encouraging individuals and groups to think about the theory and practice of the place of older people in church life comes with the publication of Working with Older People: A Resource Directory for Churches. This work, funded by the Leveson Centre and carried out by our consultant Alison Johnson over the last six months, consists of nearly 100 entries containing information about work of church-related groups with older people.

The idea for the directory had its origin in a meeting of representatives of church-related groups working with older people held in September 2002, following the ‘Ageing and Spirituality’ conference in Durham organised by MHA Care Group and CCOA. The group agreed that a mapping exercise to identify what is happening across the country would be a useful first step to closer working together. The directory aims to prevent unnecessary duplication by ensuring that people engaged in similar work are aware of each other’s involvement and can share experiences together. The directory is in four sections: national church-related organisations which are carrying out continuing work; local organisations or projects in individual churches which are either innovative or seen by local people as important enough to employ a paid worker; diocesan and similar church bodies with a particular interest in ageing issues; and individuals working in this area but not involved specifically in any organisation included in the earlier sections. An appendix lists some secular bodies which are carrying out work of relevance to the spiritual needs of older people.
The directory is an example of partnership between the Leveson Centre and MHA Care Group. We hope to make it available shortly on the Leveson Centre website (www.levesoncentre.org.uk) and plan to launch the hard copy of the directory at our third Leveson Lecture on 5 May 2004. If you’d like further information about this event then please contact the Leveson Centre or look on the website.

It is our hope that this directory will be one small step towards actualising our vision for changing the way older people are conceptualised and responded to in all of our churches today. We cannot achieve this vision without your direct support and help. The Leveson Centre has no central or local funding body and we rely very heavily on the income from the Friends’ subscriptions, the selling of our publications and support at our conferences. You are important partners with us in our shared concern for ageing, spirituality and social policy.

The Revd Dr James Woodward (Centre Director)
Alison M Johnson (Centre Consultant)

News from the Leveson Centre

Forthcoming Events

2 March ‘Seeing the person beyond the dementia’ Full details on Leveson Centre website www.levesoncentre.org.uk. Speakers are John Killick, Gaynor Hammond and Sally Knocker.

5 May Third Leveson Lecture ‘Is religion the friend of ageing?’ delivered by Professor Peter Coleman, Professor of Psychogerontology at the University of Southampton followed by the launch of Working with Older People: a Resource Directory for the Churches and a small invited seminar with Peter Coleman and Marie Mills. Details from Tel: 01564 778022.

23 June ‘Lifelong learning and older people’ Details as available on Leveson Centre website www.levesoncentre.org.uk. Speakers Alex Withnall, Joanna Walker and Jim Soulsby.


Publications available from the Centre
Six occasional papers are currently available. Cheques should be made payable to The Foundation of Lady Katherine Leveson and sent to the address on the inside front cover of this Newsletter.
1. *Understanding the Needs of Older People*, Alison M Johnson and Helen Hickman Morris, 2001 (£4.00 including post and packing).

2. *Valuing Age? An Agenda for Society and the Church*, Mark Santer (First Leveson Lecture), 2001 (£4.00 including post and packing).

3. *Committed to the Asylum? The Long Term Care of Older People*, Malcolm Johnson (Second Leveson Lecture), 2002 (£4.00 including post and packing).

4. *A GoodDeath* containing the text of six presentations given at the research symposium held at the Centre, 2003 (£5.00 including post and packing).


6. *Dementia: Improving Quality of Life* including papers presented at a Leveson seminar, 2003 (£5.00 including post and packing).

**Leveson Centre Website (www.levesoncentre.org.uk)**

In addition to news about the Centre, its publications and forthcoming events, the site now includes two papers delivered at seminars at the Leveson Centre:

‘Culture and Institutional Care – caring for older Jews in the UK’ by Oliver Valins, formerly of the Institute for Jewish Policy Research.

‘The Hidden Store: the contributions of older people to rural communities’ by Nick Le Mesurier.

It also includes a paper ‘A Survey of Ministry with Older People in the Diocese of Perth’ by Revd Stuart Good, Senior Chaplain of Anglican Homes in Perth, Australia. This paper gives an overview of issues which face society and church in the provision for, and role and value of, older people in church and society.

The site also contains details of the Christian Council on Ageing Dementia Group and its publications and a resources list ‘Spiritual Needs of Older People’ which lists relevant books, articles and organisations.

**Other events and projects**

**News**

**King’s Fund**

The new CEO of the King’s Fund is to be the BBC social affairs editor Niall Dickson.
Church of Scotland

Ten of its care homes that were due to close for financial reasons have been saved as a result of working in partnership with local authorities.

National Care Forum

This forum which consists of twenty not-for-profit care organisations managing 575 care homes has just appointed as its director Des Kelly, formerly of BUPA and the Social Care Association.

Alzheimer’s Society

During the twelve years that Harry Cayton was CEO of the Society, income rose from £1.4 million to £28 million and public awareness of the condition rose from 13% to 96%.

Hartrigg Oaks

A feature in The Guardian (10 December 2003) reports on the three-year independent study of the Joseph Rowntree Foundation retirement community carried out by York University which showed that 83% of the 200 residents were satisfied that the retirement community had fulfilled its promises of providing a home for life. By paying the community fee the risk is shared and this joint fund covers community expenses and support services including full care as required. The downside is that to be eligible for Hartrigg Oaks residents have to be well-off and relatively healthy when they arrive. John Kennedy, their deputy director of care services, will be speaking at the Leveson Seminar on retirement communities on 2 November 2004.

Home from Hospital

Gloucester Care and Repair’s Home from Hospital scheme managed by Hanover Housing Association has just won an award for Good Practice in Partnership Working. The scheme seeks to ensure flexible working between health, social services and housing when an older person is ready for discharge from hospital. A case worker makes an overall assessment, provides a single point of contact and co-ordinates all the services involved.

Anchor Trust

Alexandra House, a pioneering integrated care and housing scheme in a poorer part of Coventry is one of six such schemes developed by Anchor Trust where tenants live in self-contained flats but can join in communal activities if they wish and there are staff available on call for care. One of its particular advantages is that couples can stay together when one of them develops care needs.
Growing Older in the 21st Century

This four-year ESRC-funded programme exploring quality of life for older people has just come to an end. The reports of the 24 projects were presented at a closing conference in December 2003 and will be available in due course on the Growing Older website (www.shef.ac.uk/uni/projects/gop) Some of the many messages were to stop treating old age as an illness; treat the 25 years added to life expectancy in the past 100 years as a triumph not a disaster; and remember that older people are not a homogeneous group. The projects also highlighted inequalities in income in old age and the problems of take-up – and compared the lack of attention to older people's issues with the emphasis on younger people.

The Department of Sociological Studies at Sheffield is also home to the National Collaboration on Ageing Research. See website www.shef.ac.uk/ukncar/Reports_Findings.html

PSALM seminar 16 August 2003

David W Hill writes:

This seminar, attended by nearly fifty people, began with the Revd Paul Hawkins, Vicar of St Pancras Church describing the scope of PSALM (Project for Seniors and Lifelong Ministry) which is concerned to promote and assist ministry to older people in the Edmonton Area, and to encourage older people to develop their latent abilities and contribute to the life of the local community.

The principal contribution to the seminar was given by Ann Morisy, Diocesan Community Ministry Adviser, under the title 'A New Map of Life'. She looked at the social and cultural changes of the past few decades, which had altered our outlook and expectation of ageing. The traditional concept of life in three stages – Childhood (development), Maturity (work, home building, procreation) and Decline (senility) – saw the first and last stages as troughs, with a central peak. This was no longer tenable, people lived longer, and an extra stage had to be interposed between Maturity and Decline, the Third Age. This was a time when the goals for maturity were no longer really significant, retirement had been reached and a more philosophical view of life was possible. People in this group retained abilities and energy to harness in a variety of ways for their community. Because they were no longer tied to an externally imposed schedule they could give more freely of themselves, and find more satisfaction in their work.

There were markers for a successful third phase of life: loving, in its broadest sense, and working were the key. There was a need to structure the day; a need to open up the personality and shed prejudices and misconceptions which stunted outlook and limited activity; and a need to develop a personal spirituality.

The freedoms of the Third Age had come at a time when social changes had undermined the structure of the extended family where relatives were at hand to take care of older
people when they reached their declining years. This had opened up the need for voluntary help, in conjunction with Social Services, to provide care and personal support for older people. At the same time respect for older people had declined.

Quality of care for those in their declining years was important: they must be treated with due respect to their person and encouraged to remain as active as possible, mentally and physically. Even those affected by dementia could benefit in this way. In a Christian context, the last two phases of life should be regarded not as a trough but as a climax, leading to the fulfilment of the purpose of life as a preparation for eternity.

Her talk was followed by reports on initiatives in local churches and a presentation by Claire Pinney, the PSALM co-ordinator, who spoke of the work she had been doing, including the resources centre, the PSALM Directory and the report she had produced.

**Regional Studies Association Seminar on Demography and Ageing**

This invited seminar held at Nottingham Trent University on 7 November was an opportunity to hear a range of speakers from the UK and Europe reporting on their research into the implications of an ageing population for the 21st century. Richard Baker of Age Concern England spoke of the ‘Regions for All Ages’ programme reported on in previous issues of this Newsletter. This was followed by Ross Brown and Mike Danson who outlined the effect of demographic change on the labour market in Scotland – a nation where overall population is declining and thus the retention of older workers is very important.

A presentation by Joos Fortuijn of the University of Amsterdam reported on work carried out on the daily activities of older adults in six European countries which was co-ordinated by Professor Clare Wenger from the University of Bangor. This highlighted the importance of health and activity in continuing well-being in older age. Anne Green of the University of Warwick looked at regional and local labour market prospects taking Cornwall as her case study and this was followed by a paper on Third Age enterprise and the increase in entrepreneurs at that stage of life.

The penultimate paper was a fascinating overview given by Jacqui Spradbery of Age Concern and Professor Irene Hardill, who had organised the seminar, on the challenges and problems of migration to Spain as a retirement choice. The seminar concluded with an outline by Alec O’Neil of the Joseph Rowntree Foundation of older people’s priorities in research and development. He reminded the audience of the disability mantra ‘nothing about us without us’ and pointed out that this applied equally to research into ageing issues. Older people wanted consideration to be given to their lives rather than to service solutions.

For further details of any of these papers e-mail sandy.palmer@nyu.ac.uk
Graham Lecture

Counsel and Care’s 2003 Graham Lecture was given by Dr Hans Becker, CEO of the Humanitas Foundation in Rotterdam. Dr Becker described the homes he inherited ten years ago as ‘islands of misery’ with an institutional feel and shared rooms. He set about transforming the organisation based on four basic values:

1 Individual control – residents can have what they like when they like, for example coffee as you like it in a cup or a mug as you choose. Staff help ‘with our hands on our backs’.

2 Individual activity – instead of a life with no money and no activity and too much time to think about problems, residents are encouraged to continue to do whatever they can – ‘use it or lose it’. ‘Too much care is worse than too little care.’ ‘Anything is better than doing nothing’.

3 Positive attitude – a ‘Yes’ culture. Staff respond positively to residents’ ideas for improvement. If, for example, a resident wanted to bring her dog into the home, consideration was given to the minuses – hygiene, dirt and so on – and to the pluses of giving the resident self esteem, a continuing role in caring, something to talk about and exercise taking the dog outside. Unless the minuses outweigh the pluses, go for it!

4 Extended family approach – residents are no longer an island but part of a community with staff, volunteers, pets and so on. 40% of staff come through personal contact and people want to work there. ‘Reintegration rather than distintegration’ and direct contact with the neighbourhood.

Some other key points made by Hans Becker included:

- Restaurants and bars are a meeting place where the food tastes nice and conversation is encouraged through interesting murals. ‘The lady behind the bar is more important than the dietician.’ ‘The profit is in happiness.’

- Apartments for life – varied tenures and care delivered in each resident’s own home for the rest of their life.

- Communication – he doesn’t believe in policy notes for staff but management by stories which illustrate good practice and one-liners which encapsulate his philosophy.

- Creativity – residents and staff are encouraged to come up with creative solutions, for example a tassel attached to the door to help a wheelchair user close it.

- Mixed occupation – those with dementia with those without, those in wheelchairs with those who are mobile, the rich and the poor, the well and the ill, the younger and the older, spouses kept together.
Meetings – do the results of any meeting justify taking staff away from care of residents?

Humanitas now has some 4,000 older people living in its apartments, residential and nursing homes. The audience went away excited by the vision and enthusiasm of Hans Becker. For more information e-mail info@humanitas-rt.nl

Church Army

Please note that the Church Army headquarters is now in Sidcup. The address is Church Army, Marlowe House, 109 Station Road, Sidcup, DA15 7AD, Tel: 020 8309 3509, E-mail: information@churcharmy.org.uk

Forthcoming events

3 February  ‘Ageing and the brain – use it or lose it?’ Help the Aged Annual Lecture, London. Details from Chris Bray, Tel: 020 7239 1928, E-mail: info@helptheaged.org.uk

5 February  ‘Intermediate care and dementia’ Free workshop from the Change Agent team at the Department of Health to be held in Birmingham. Details from E-mail: jewyn@dementia-voice.org.uk


9 February  ‘Running a workshop on commissioning for falls and fracture prevention services’ Free workshop from the Department of Health. Details from E-mail: Naomi.Gray@doh.gsi.gov.uk

26 February  ‘Promoting the spiritual life of residents in care homes: a wider dimension to caring’ St John’s House, Winchester. Details from Tel: 01962 854226, E-mail: office@stjohnswinchester.co.uk

20 March  ‘Strokes: understanding the aftermath and confronting the challenges’ PSALM, St Pancras Church, London. Details from Claire Pinney c/o St Pancras Vicarage, 6 Sandwich Street, London, WC1H 9PL.

25 March  ‘The resources and needs of the elderly’ Speaker Revd Albert Jewell. St Michael’s College, Cardiff. Details from Tel: 029 2087 4240 or Religious and Theological Studies Department, Humanities Building, Column Drive, Cardiff, CV10 3EU

27 September – 1 October  Third International Conference on Ageing and Spirituality with a special emphasis on palliative care. Adelaide, Australia. Details E-mail: c.gliddon@csu.edu.au, Website: www.centreforageing.org.au
News update

Longevity is not a threat to the NHS

The British Association conference in September was told by Professor Raymond Tallis of the University of Manchester that although nearly two-thirds of the increase in longevity in the human race has taken place since 1990, the ageing population is not a threat to the NHS because the amount of dependency and disability before death declined the longer someone lived. People enter old age in much better health than previously. For example between 1980 and 1991 the proportion of men over 85 able to bath, feed and get to the toilet unaided rose from 69% to 79% and the proportion of women from 64% to 80%. He also reported a marked decline in the age-adjusted risk of dementia.

Carers

Carers UK reports that information from the census provided by the 5.2 million carers showed that many of those providing heavy care, that is more than 50 hours a week of unpaid care, are themselves in very poor health. More than 225,000 reported in a survey that they were ‘not in good health’. Amazingly nearly 4,000 people over 90 are providing 50 or more hours of care a week.

Long-term care: statement by Royal Commissioners

In an unprecedented move, nine members of the Royal Commission have published a second report calling on the Government to implement in full their 1999 recommendations. The statement revisits the report in the light of developments since it was published and confirms its original conclusions that nursing and personal care should be free at the point of use in both residential and domestic settings. The members see that as ‘a just, principled and affordable way of meeting a pressing social need’. They also ask again that a National Care Commission should be set up with, amongst other responsibilities, a brief to oversee research into these issues. For details see www.ltc-commissioners.org.uk

Falls

National Service Framework Standard Six aims to reduce the number of falls which result in serious injury and to ensure effective rehabilitation for those who have fallen. The Department of Health has recently published a workbook How can we Help Older People not Fall again? Implementing the Older People's NSF Falls Standard: support for commissioning good services which outlines a design piloted by Greenwich PCT for a workshop for senior commissioning staff in a PCT or group of PCTs and Local Authority partners to help them review the pros and cons of investing in falls and fracture prevention services in their area. For further details see the DOH website www.doh.gov.uk/nsf/olderpeople. A press release dated 22 December gives examples of simple measures which NHS Trusts have taken to cut the level of falls. These include specially designed slippers and giving older people night lights which come on automatically when they get up in the night.
The Help the Aged Preventing Falls Programme is developing resources to address the high incidence of falls in care homes. They want to collect information about what works in the areas of assessment, support for staff and residents and action on environmental risks. The project leader is anxious to make contact with homes working in this area. If you would like to contribute to the research programme please e-mail Sarah.Buchanan@helptheaged.org.uk before the end of January.

Super complaint

The Consumers’ Association and members of the Social Policy Ageing Information Network (SPAIN) of which the Leveson Centre is a member, have used the Enterprise Act to submit what is known as a ‘super complaint’ calling for a formal investigation by the Office of Fair Trading into the ‘dysfunctional’ care home market. The OFT has pledged to ‘fast-track’ the issue, and report in 90 days’ time on whether it will carry out a full investigation.

The super complaint focuses on two particular areas of concern. First, many local authorities pay insufficient fees to independent sector providers and then expect local authority residents and their relatives to top up inadequate fees. Secondly, some self funding residents are being charged more than those funded by the state in order to compensate for the shortfall. The charities also point out that care home residents and their relatives in general lack ‘accessible and reliable’ information, and are frequently misled by complicated contracts.

Criminal Records Bureau

Some care home associations have joined forces to plead with the Government to reverse its decision not to allow new staff to start work before their record has been checked by the CRB.Shortly before the deadline of 1 October 2003 the National Care Standards Commission said that it would ‘exercise discretion’ on a case-by-case basis when dealing with homes that had not completed CRB checks.

Following the doubling of fees last July, the costs of applying are to increase yet again from April 2004. A standard check will rise from £24 to £28 and an enhanced one from £29 to £33. The Government also plans to charge registered bodies £300 a year to apply for checks.

Commission for Social Care Inspection

At the annual Social Services Conference, shadow chairperson Denise Platt set out her priorities for CSCI. This included the following statement: ‘We intend to take an early look at the regulations to identify where they, or the current practice of enforcing them, may get in the way of good commissioning … For example – there is some reported experience of older people having to be moved from their residential care home around the system if they have dementia. This is because the home may not have proper registration – even though the home may be willing and competent to provide the care the person needs.’
Elder abuse in care homes

Following a number of recent reported cases, the Commons Health Select Committee is carrying out an inquiry into elder abuse. In its submission, the charity Action on Elder Abuse (AEA) has accused the Nursing and Midwifery Council (NMC) and the National Care Standards Commission (NCSC) of repeatedly failing to investigate properly the abuse of older people or take action against the perpetrators. The charity also suggested that the NCSC was giving greater priority to its public image and its relationship with care home owners, rather than ensuring quality care for vulnerable older people. In its view rooting out elder abuse should have been a standard in its own right in the National Service Framework for Older People.

Early Day Motion

Thirty-eight MPs have signed an Early Day Motion deploiring comments made by Stephen Ladyman stating that there is no national crisis in the care home sector. The EDM calls on the Government to take ‘meaningful action to significantly reduce the current rate of care home closures and combat the decline in the availability of domiciliary care’.

Building on the Best: choice, responsiveness and equity in the NHS

A document with the above title whose main architect was Harry Cayton, the ‘patient tsar’ (formerly CEO of the Alzheimer’s Society), was published on 9 December 2003 and sets out how the Government intends to make NHS services more responsive to patients, by offering more choice across the spectrum of healthcare. For full details see www.doh.gov.uk/choiceconsultation

Supporting People

An inquiry to be conducted by Eugene Sullivan, the head of public sector services at RSM Robson Rhodes, will investigate the claim that the Supporting People budget has been increased because social service departments have used the new programme to pay for their existing community care services that it was never intended to fund – a practice known as ‘cost shunting’. It will also look at the wide variation in support costs between authorities. Some councils have Supporting People costs of only 19p per person, whereas others have costs of £3.81 per head.

Ministers have agreed to provide an additional £400m for this year – the first year of the new programme – which will be administered by local authorities.

Imogen Parry of EroSH (the national consortium campaigning for sheltered housing) has pointed out that, because sheltered housing has much lower staff costs than other forms of supported housing, the relatively low costs of support services for older people (on average £6.84 per week) represent extremely good value for money.
Delayed discharge

A report from the House of Commons Public Accounts Committee suggests that despite the halving of delayed discharges since 1997, there are currently 3,500 over-75-year-olds awaiting discharge of whom almost a third remain in hospital for over a month and are often those with the most complex needs. The report urges the Department of Health to devise strategies to discharge these people. See Ensuring the effective discharge of older patients from NHS acute hospitals at www.parliament.uk

The new system of fining local authorities came into effect in shadow form at the beginning of October 2003 and local authorities are announcing a variety of plans to spend their delayed discharge grant ranging from additional intermediate care beds, through investment in hospital social work teams to employing extra home care staff.

Local facilities

Tessa Harding of Help the Aged has written: 'Location is an important consideration … Access to local shops, post offices, places of entertainment and community activity … the availability of public transport, location of bus stops … can all make a difference in how mobile older people are able to be and how safe they feel.' A Help the Aged project and publication concerned with older people and local facilities is being planned. Contact Alan Burnett (Tel: 020 7239 1884) if you are interested in being involved in this initiative.

Liberal Democrat policies on the Third Age

In their continuing emphasis on policies for old age, the Liberal Democrats have set up a special working group on the Third Age, chaired by Nick Clegg, an MEP. The group will formulate policies for consideration at the 2004 party conference. These may include a flexible decade of retirement, a one-stop shop for advice, credit schemes for older entrepreneurs and the retention of police officers past retirement age.

Recent publications

Notices

Age Today Issue 4: Housing, Homelessness and Older People
Each issue of Help the Aged’s journal Age Today concentrates on a specific topic and this one provides an excellent overview of current issues concerning housing and older people such as sheltered housing, co-housing and home share, a rough guide to supported housing, making decisions and seeking advice. Age Today is available from info@helptheaged.org.uk
Ageing, Spirituality and Well-being

This book, published last year and edited by Revd Albert Jewell, brings together the papers from the International Conference with this title held in Durham in 2002. The papers explore how the particular spiritual needs of older people can be defined and addressed and how meaningful care and support can be given. Published by Jessica Kingsley, ISBN 1-84310–167–X, £17.95.

Memory’s Tomb: dementia and a theology of Holy Saturday

This is the first in a new series of Aspects of Ageing Papers from MHA Care Group which hopes to build on the solid foundations laid by the Halley Stewart Age Awareness Project. Written by an ordinand in the URC, Suzanne McDonald, it attempts to find a theological language for dementia in the light of Alan Lewis’s exploration of Holy Saturday as a no-man’s land and time of waiting. She relates this to Malcolm Goldsmith’s ‘remembered by God’ model and concludes that ‘we can offer the true depths of God’s promise that our identities are upheld in God’s own remembering’. Available price £1.00 by e-mailing Lynn.Fox@mha.org.uk

All our Tomorrows

The Association of Directors of Social Services and the Local Government Association have combined to produce a paper which argues that services for older people should be commissioned in accordance with a local strategy drawn up by an older people’s partnership board which would include input from the local community, housing, social services, health, leisure, education and the voluntary sector. See www.lga.gov.uk

End of Life in Care Homes: a palliative care approach

Edited by Jeanne Katz and Sheila Peace, this book provides an excellent review of policy developments and changes in this area supplemented by data from two Open University studies to emphasise the extent to which concentration on quality of life has overshadowed good practice in end-of-life care. Chapters include managing dying residents, the needs of relatives and training for care workers. Published by Oxford University Press, ISBN 0–19–851071–3, £24.95.

Alone with Dementia

This book written by Margaret Jeremiah has been published with the assistance of a grant from Millennium Awards. In the Foreword Professor John Wattis (a member of the CCOA Dementia Group) writes:

The area of spirituality and dementia is currently enjoying a great deal of interest. The Christian Council on Ageing has a Dementia Group that has been working for ten
years to raise awareness of the spiritual needs of people with dementia. It has taken a broad approach, recognising that people express and satisfy spirituality in different ways. For some people formal religion is the key. Others take a more humanistic approach, concentrating on the importance of interpersonal relationships as mediators of meaning. Quakers testify to ‘that of God in everyone’ and in some ways bridge the gap between the more formal religious expression and those who would do without God altogether.

The account you will read here comes from a Quaker perspective. It is a moving personal account, from the perspective of a loving partner taking on the role of ‘carer’, of the unfolding of a dementing illness, complicated by poor sight. It shows many of the triumphs and failures of current services. If you are reading this as a family member or friend of someone with dementia, it may help you feel less alone. If you are reading it as a professional provider of services, I hope it will move you to redouble efforts to provide services that are sensitive to the human needs of both people with dementia and their friends and families. If you are reading this as a commissioner of services or as somebody with political ‘clout’, I hope you will consider how you can ensure fair priority to improving services for people with dementia and their families.

Available from the author Margaret Jeremiah, Ithaca, Boat Dyke Road, Upton, Norwich, NR13 6BL. A donation of at least 50p to cover the costs of postage and packing would be appreciated.

Reviews


This modest-looking publication works on many levels, including as a metaphor for its subject matter. Older women can appear unassuming and with little to offer to the main concerns of busy parish life. This book offers no academic pretensions in its style of writing or the look of its text and layout. It does, however, deal with profound matters and is based on doctoral research. The professional and lay person alike would benefit from its direct approach.

For example, as well as explaining about the theory of narrative both as a device for research and as a means of self development and change, the author uses the stories of older women (in her words, and in their own) to illustrate her research-based proposition: that older women and the church need community, connection and care. Insofar as they both need these three things, their interests are mutual and should be taken more seriously, become better understood and be better nurtured.
Janet Eldred describes herself as a mid-life American woman who has lived most of her adult life in the urban north-eastern US, within a diversity of Christian faith communities. She found that the issues that fired her professionally – feminist theology and older people – were coming together with another powerful driver: she wanted to prepare for the older Christian woman she hoped one day to become. She thus acknowledges that researchers can have personal motivations as part of their professional curiosity, and is prepared to say that this self-understanding led to her comparing her subjects’ experience with her own. This prompted further questions and analyses in her mind, to do with how and why older women continued to work at their faith, their spirituality and their churches, often in the teeth of discouragement and ageism.

None of the above will sound surprising to feminist researchers, including those within the fields of gerontology and theology. For the novice in these matters, Eldred includes an appendix on feminist theology, in which she defines terms and outlines current debates. Whether or not her statements would meet with universal agreement amongst proponents I cannot tell, but her guidance gives the reader a handle on the subject and suggestions for further reading that seem most helpful (speaking as a gerontologist, relatively new to its relationship to theology and spirituality).

The meat of the book, drawing on data generated for her doctoral studies of older women members of UK churches, comments on how community, connection and care are illustrated in the stories of three particular women in their (lifelong) experiences within faith communities. We see through their narratives the historical as well as the current factors in their relationships, their attitudes to change, their sense of home and belonging, their self identity as expressed through giving and receiving service. (You can try something similar at home yourself by tracing your own ‘faith journey’ – it’s quite instructive!) So whilst the book is not about pastoral care, ageism, personal change or mature identity, all of these things are there.

Lastly, Eldred seeks to apply her reflections to practical situations in local and church communities, noting that some churches have begun to recognise their mutual dependence with older members and older people’s unique status. Others are still in need of great encouragement to recognise that older people have gifts as well as needs, and of help to move away from indifference and ageism.

If encouragement does not work, Eldred suggests, there is a warning that the next generation of older women will not be so accepting of low status and lack of recognition within the church. One of the narratives she has featured is quoted as saying that not having a church connection would be ‘like spring without flowers’ (the source of the book’s title). The warning is, therefore, that this attitude may pass with the current generation of older women. Tomorrow’s elders will find belonging, support and spirituality in various places, which may or may not include the church. They will be less likely to align themselves for life to particular denominations or doctrines.

Even so, churches could remain important communities where women gather and nurture that special connection known as fellowship – which knows no age or generational boundaries. Mature and older women’s spirituality has much to teach the local church
about their essential connectedness within their communities as well as their resilience and means of thriving.

Eldred would be the first to point out that her studies have been small scale and partial, and need repetition on a larger and more diverse canvas. She has, however, provided a framework and some propositions to work with, which have potential for many areas of study within pastoral and theological fields. For gerontologists, there are issues of interdependence, community support and quality of life, to name but a few points of interest. MHA Care Group is to be congratulated on encouraging the publication of such an interesting and unusual ‘work in progress’ so that its thinking and findings can be shared at an early stage.

Joanna Walker (University of Surrey and Diocese of Guildford)


It is refreshing that as a young curate Rob Merchant chose to address an area of church life and ministry which is often left to those who are themselves certainly in the Third Age! His book examines current and future issues facing older people and the church and combines gerontology and theology with practical insights into the implications for churches of the major changes coming about with the ever increasing numbers of Third Agers in society. He begins by looking at the current situation with statistics and quotations about ageing and then moves on to look at ageing in the Old and New Testaments. This is followed by a chapter on the early church which some may find rather less useful or relevant.

It is encouraging that his conclusions which take a further two chapters challenge the view of older people as ‘yesterday’s church’ and clearly state that ‘To reach younger generations is vital, but the consequence of an unbalanced approach will be to repeat the failure of previous generations that never prepared older members to pass on the baton of faith and leadership because they didn’t know how.’ He also refreshingly presents old age as an adventure rather than a time when one is pushed into the periphery of society.

This relatively short book should stimulate evangelical and other churches to take more seriously the spiritual needs of those who form a majority in most, if not all, of their congregations.

*Alison M Johnson (Centre Consultant)*
Contributions

All-age worship

Revd Dr David Isiorho, Rector of the Faxton Churches Group in Leicestershire, originally wrote to the Church Times challenging the view that ‘the only people really worth having in church are young people’. We invited him to elaborate on this theme.

I see the shires as the precious repository of the Church of England tradition. Careful nurture in the rural context could prove vital for our very survival over the next few decades. However, rural churches often feel abandoned when young people from urban shadow villages go to church in towns claiming that their local parish does not have the resources to offer them lively worship styles.

There has been a great interest in family services and so-called all-age worship for many years now. Having tried these things myself and found them wanting, I no longer have an enthusiasm for such an approach. As a sociologist I know that most people don’t live in nuclear families and that we are becoming in the UK a much older population with many people living on their own. It may not sound fashionable but I would like to make a case for honouring anyone of any age who is willing to attend church on a regular basis. Our prayer is that more people will want to do this as an expression of their genuine love for God as revealed in his Son Jesus Christ.

All-age worship has a familiar and over-worked theme, namely that the only people really worth having in church are young people because they are the future. To add sophistication to a simplistic argument it is also acknowledged that young people are the church of tomorrow. Presumably an older congregation which is considered to be undesirable is the church of yesterday. However, many young people drop out of church to return later in life and are joined by many others who had no former experience of church at all. Sometimes people get involved following bereavement and a funeral conducted in a way that made sense to them. Let’s stop this nonsense and recognise that the only church that really matters is the church of now – the church of today.

So why is so much being invested in the youth and not the experienced members of the congregation? Does not the church of yesterday inform our practice for today? And how relevant is the concept of the church of tomorrow for our purposes? Our Lord could return any time and churches are not required in heaven any more than sacraments.

Many so-called all-age worship services are little more than play groups that may include the odd prayer or spiritual song. Having little experience of normal worship it is difficult to see how they could remain part of the church of today let alone form the church of tomorrow. Young upwardly mobile parents often use the children as an excuse for their infrequent communion and lack of attention to the liturgy and make far more noise than their children ever could. My response to their fears about children making a noise in church is not to worry – I can always raise my voice! Attending tailor-made services for
children does not encourage young families to come to the Lord’s Table or nurture them in an understanding of the worship and life of the church. Rather it gives them a further opportunity to opt out.

A thriving Junior Church in a rural benefice will be seen by many people as a sign of the kingdom. Sadly they could be mistaken. If the Sunday School or Sunday Club as they are often called has been set up by a group of parents exclusively for their own children then it is not going to last very long. Once the children are in their teenage years they start to drift off to all-singing and all-dancing churches elsewhere.

We should remind ourselves that we are here to build the Kingdom of God. Young people are important but so are older people, some of whom have been faithful throughout their lives and stayed within the household of faith. We should discover, and help to release, the blessing of the diversity of gifts within the whole church. And that means accepting difference. Rural and urban churches are clearly different as are young people and older people and for that very reason we need to find new ways of working together in the here and now. For all are made in the image of God and redeemed in the blood of Christ.

In this partnership we truly can develop an informed and vibrant community of Christians who believe in and live by the gospel. The dynamic implications here for mission are important and exciting. We should seek to be neither the church in waiting nor the church in hiding but the church in action here and now. In this way we can continue our threefold vocation to be holy, catholic and apostolic.

Death is enjoyable

John Bowers was born in 1912. After working as a District Commissioner in the Sudan, he served during the war in Abyssinia and North Africa. From 1947 he was Head of the Adult Education Division of UNESCO. He was also adviser to the Ministry of Overseas Development and drafted the first Government White Paper on National Parks.

I suppose that for many old people the fear of death is one of the most disturbing anxieties of old age. Anything that can remove or mitigate it must be welcome. This thought leads me to recount a personal experience and to suggest how it might be put to good purpose.

In 1942, on a Commando raid in the Sahara Desert, I was ‘blown up’ by a bomb accurately aimed by a German pilot – a Near Death Experience (NDE) which I greatly enjoyed. You may find this hard to believe but I am deeply grateful for it. The 500lb bomb detonated within a few yards of where I lay in the sand. I was instantly enveloped in a luminous cloud of pale purple light and a thunderous roar of sound. It was an ecstatic sensation and I felt no vestige of fear or pain. Then I was happily floating, apparently twenty feet or so above the ground, looking down at my body as it was flung over backwards. Soon I was gliding up a tunnel that seemed to be made of translucent silk towards a circle of primrose
coloured light. I clearly remember saying to myself: ‘If this is death it’s rather dull’ (I think in retrospect I meant uneventful). As if in response to this negative remark, I felt myself being sucked back from the light and squeezed into an unpleasantly heavy body. I will spare you the details of what followed my return to earth, of the unenjoyable 33-hour return journey over the desert, face down in a truck, and the eleven months of hospital treatment and thirteen surgical operations that followed.

Although I remembered the experience very clearly, I did not think or speak much of it. It was many years later when I began to write my life story that I realised how deeply it had influenced my beliefs and behaviour.

The most convincing impression I recall was that I – the essential Me – was ‘up there’ looking down at my body. This conviction is expressed by almost all of those who have reported NDEs.

Brought up in the Church of England, I learnt in my childhood that I was a body that had a soul. I imagined it as some sort of ghost that would go to heaven when I died. I have now come to believe rather that I am a soul that has a body. This seemingly trivial shift of belief has led to many others.

If I can apparently leave my body and move weightlessly or free of gravity when my body is close to death this seems to indicate, though not, of course, to prove, that I am an immortal soul capable of existing beyond bodily death.

The belief in immortality and the ‘separable soul’, logically leads to a belief in incarnation as the common experience of mankind. This logic has led me into sympathy with Hindu and Buddhist beliefs. It has also deepened my belief in the incarnation of the divine ‘Christ Spirit’ in the human body of Jesus and his transcendent immortality.

When I was apparently a free-flying non-physical entity out of my body, which was ‘lying low’, traumatised and evidently unconscious, I still seemed to possess the faculties of my physical brain considerably enhanced – notably acute clarity of vision, memory and command of language. It seems therefore plausible to assume that as an immortal soul I have an immortal, non-physical brain with super-sensory consciousness and that I shall retain this and its memories of ‘previous lives’ after bodily death.

I even have a persistent belief that as an incarnate soul in a human body I have two ‘brains’ – a physical brain and a soul brain – now integrated by the process of incarnation. I find support for this from the German mystic Rudolf Steiner, founder of the Anthroposophy movement, who writes of the Soul Organisation.

I was drawn back before I reached the light at the end of the tunnel. Many ‘returnees’ report how they went ‘through the light’ into ‘non-physical reality’ – an extra-terrestrial sphere. Was this what Jesus called his father’s house of many mansions? Most of the ‘returnees’ report meetings with deceased relatives, ‘Beings of Light’ and various religious
figures and many experience a life review – an instantaneous and helpful replay of their earthly life.

After return to my body I had no sense of how long I had ‘been up there’. It cannot have been long because the German planes were still strafing us. A cannon shell hit the truck beside me with a sharp metallic clang. I still felt no fear and, remarkably, no pain, only a sort of light-headedness that was not unpleasant. Many years later, ruminating on the sense of being outside time, I recalled the strange feature of the NDE that I seemed to see the actual event that caused the experience. Did I ‘go backwards in time’?

I can readily empathise with rational materialists, and indeed anyone educated in our sceptical scientific culture, who finds NDEs incredible – mumbo-jumbo is the term often used. Hallucination, possibly triggered by endorphins is a favoured explanation. But those of us who have had an NDE or any kind of OBE (Out of Body Experience) seem almost unanimously convinced of its reality.

What then is the relevance of Near Death Studies to older people’s fear of death? I have found that many people who have learnt that I have had an NDE are eager to hear about it and many seem to gain assurance from the idea that death may be enjoyable. This assurance might well be transmitted in a friendly talk by someone who appears honest and normal and will tell of their experience without sensationalising it and without any motive of conversion or fostering a change of belief. There are a surprising number of people who have had NDEs and OBEs and some could surely be enlisted to do this service.

As many live to be old, how can we enable older people to find fulfilment?

Dean John Petty moved to Shrewsbury from Coventry Cathedral at the end of 2000 to be Chaplain of The Mount House Residential Home. These are some extracts from a sermon that he preached at Temple Balsall at the end of the Heritage weekend in mid-September.

I want to highlight a particular very elderly Japanese lady. She features in a book of stories of old people put together by Michael Henderson. Shidzue Kato spanned the 20th Century. In the 1920s she pioneered birth control in Japan and in the 30s developed it so well that she was put in prison. After great suffering in the Second World War she entered politics, moving from the House of Representatives on to the Senate in the 50s. She sought peace with nations, persuading Prime Ministers to apologise for their behaviour, especially to Korea. In later life she received many awards recognising her stature. In her 90s she started writing letters in pink envelopes. They have become famous, directed towards people from the Prime Minister downwards. I quote two short extracts.

‘If people appreciate the efforts of others by sending letters,’ she says, ‘those who have received letters will be encouraged to do some other good things again. This kind of gesture will prompt people to behave in the right way.’ She plans to start sending her pink letters to people overseas. ‘I am ninety-five years old, but still curious to do something for
society and women,’ she says. She sees Japan becoming a big power economically but becoming poorer and poorer spiritually. ‘We must try to stop this slide,’ she says. ‘Many point to Japan and China as world leaders in the twenty-first century. Japan must take responsibility for the welfare and prosperity of the world.’ A quick picture of an old, old person still full of life, using her maturity to encourage others and trying to stop her country becoming poorer and poorer spiritually.

Is not this what we could see of many older people in this country? I remember Malcolm Muggeridge saying that it is an animal disposition to believe that millions are more important than one; it is the gift of the spirit to know that one can be more important than millions, and you can be that one.

We are here because Lady Katherine Leveson understood just that. She could see that the spiritual values need to be fostered as much in the very old as in people who are young and somewhere in between and I am thrilled that James Woodward has taken up the cudgels on her behalf, backed by a great Board of Governors and a splendid staff who are doing just that.

Some of us are exploring, day by day, through shared services and prayers the way of encouraging residents of nursing and residential homes – as it were transplanting the heritage of such places as Temple Balsall into secular residential homes that proliferate throughout the country. We have established ‘The Simeon Trust’, Simeon being the old man who held our Lord, as a baby, in his arms. The Trust is to encourage Chaplains to explore the spiritual dimension in each elderly person.

May I take as an example two people who came to yesterday’s service at Mount House Shrewsbury? Nancy is Welsh. When I put the hymn book we have printed into her hands she says, ‘It’s heavy’. Nancy sang in her church choir and knows much of the prayer book. Jean is her great companion. Jean once worked for the British Council in Lisbon. They are inseparable. As you push one wheelchair alongside the other both faces light up; but if you ask them the name of their friend, they couldn’t tell you. A constructed sentence is beyond them and yet the Lord’s Prayer, The Nunc Dimittis, and the Book of Common Prayer responses flow out.

They arrive at the service laughing and joyful to join others who are totally switched on, and waiting to pray for Iraq, for Sweden on its vote for the Euro after the terrible murder of Anna Lindh the Foreign Minister, and to pray for other members of the Home who are not well or in hospital. They offer names for prayer and they pray. These residents, mostly in their nineties, may not be writing pink letters to Prime Ministers but they have found a new raison d’être in prayer and worship and they have a new structure to their day. This heritage, that has been with the Lady Katherine Leveson Foundation for hundreds of years, is becoming now the new heritage for the elderly in secular fields.

The Revd Sam Kobia, the new Secretary-General of the World Council of Churches, says, ‘I believe that the 21st century will be a century where spirituality will take centre stage in our lives.’ This is true, and we all can contribute by making the best of our lives at all
stages, so that rather than the quip ‘Old age comes at a bad time’ we can say ‘Old age comes at a good time.’

The Ombudsman’s Report: what about people with dementia in residential care?

Originally published in the CCOA Dementia Group Newsletter, Paul Green, staff nurse at the Priestley Unit, Dewsbury and District Hospital writes:

The Health Service Ombudsman’s recent report on NHS funding for long term care reaffirmed the judgement reached in the 1999 Coughlan case which ‘resulted in clarification of the law that where the primary need for accommodation was a health need, the whole of the care package, including accommodation, was the responsibility of the NHS.’ However, the Department of Health’s failure to provide clear and detailed guidance concerning eligibility criteria for continuing care funding has allowed health authorities to apply their own restrictive rules resulting in unjust decisions and financial hardship for some individuals. In the complaints that have been upheld, patients were denied NHS funding when their nursing home care was clearly not ‘merely incidental or ancillary to the provision of accommodation or of a nature one could expect social services to provide.’

Under the Health and Social Care Act (2001) those who qualify for the top tier NHS contribution towards the cost of nursing care (which applies in England only) have been assessed as having significant health needs that may involve specialist intervention, a definition which suggests that their need for accommodation is determined by poor health. There are patients with dementia in EMI nursing homes who fit into this category and would thus benefit from a full implementation of the Ombudsman’s findings by receiving NHS funded care. Relatives of these patients should therefore seek to have their cases reviewed and apply for continuing care status.

Any increase in NHS funding for long term care is welcome but it is important to remember that the majority of people with dementia will remain unaffected. Many of them live in residential homes, receiving no NHS contribution towards the cost of care and little, if any, input from specialist mental health services. EMI nursing home places are reserved for those who are restless, agitated, aggressive or otherwise difficult to manage. As Gill Parker points out, ‘By and large the NHS has abandoned people with dementia. Like Mrs Rochester they have been put away in the attic and we pretend they are not there. As life expectancy increases, this will become a growing problem. Surely it is time to open the attics and face the realities.’

This can only be achieved if the statutory services accept that a person with dementia’s need for accommodation in a residential home is determined by a mental health problem which numbers a loss of independent living skills among its effects. The NHS should
support home owners to ensure that their staff receive dementia care training and provide a suitable range of therapeutic activities. Regular input from mental health professionals and an NHS contribution towards care costs would help to achieve this and begin the move away from decades of neglect. The Ombudsman’s report is a partial opening of the door to a world where people with dementia are properly cared for by society instead of being excluded from the mental health system once their needs have been assessed and then expected to pay for the privilege, but there is still much to be done.

References


**Pension credit where pension credit is due**

_Roy Allison, Chair of the Christian Council on Ageing writes:_

Pension Credit was introduced in October 2003 to provide extra money for half the pensioners in the country. The concept of Pension Credit is very simple: extra money is given to pensioners with modest means. In particular this is intended to help pensioners who have a small occupational or personal pension or modest savings.

Some intended recipients have been easy to identity, for example those previously in receipt of the Minimum Income Guarantee (MIG). But the identity of many other eligible pensioners is unknown to the Pension Service. Therefore they have to apply for Pension Credit.

The graphs in the Pension Service booklet on Pension Credit (PC1L) appear to indicate clearly the basis upon which eligibility is determined. But as with all such schemes, some of the details are quite complicated. For example a pensioner paying interest on a mortgage might receive extra help because the amount of interest paid is deducted from a pensioner’s income before Pension Credit is assessed.

One pensioner was concerned whether the extra money would reduce her Council Tax Benefit. The answer is that Pension Credit is taken into account, but the net result should
be that the amount of Council Tax to be paid is not increased. Indeed in some circumstances Pension Credit could reduce the amount of Council Tax to be paid – and in very exceptional circumstances it could reduce Council Tax to zero!

Although pensioners already claiming MIG should have been transferred to Pension Credit, thousands of pensioners eligible for MIG did not claim it. Now millions more pensioners are eligible to receive Pension Credit. Andrew Smith, Secretary of State for Work and Pensions, expects one third of eligible pensioners not to claim it. David Willetts, Andrew Smith’s Opposition shadow, has calculated that the Chancellor can keep within his Golden Rule on Government borrowing only because of the anticipated £25 million of unclaimed benefits left in the Treasury coffers by the end of 2005/6. It is surely inequitable that it is potential benefit recipients who are ensuring that the Government’s books balance.

It is therefore accepted that many pensioners will not claim Pension Credit, unless more effort is made to bring it to pensioners’ attention, and this is what the Christian Council on Ageing (CCOA) is seeking to do. CCOA’s interest is not to promote a government policy as such, but to ensure – as far as possible – that older people who are not aware that this extra money is available, actually receive it.

There are many pensioners who have not enough money both to heat their homes and eat properly. One pensioner said to me on the last Sunday in December that she sets her central heating to go off at 9am each day, because she cannot afford to keep it on all day.

That conversation took place in a church, following a service. So it is to be hoped that it is not necessary to make the case for the relevance of the Christian gospel to people’s needs. It is surely sufficient to remind ourselves of the second greatest commandment and the parables of the Good Samaritan and the Sheep and the Goats. Ensuring vulnerable older people receive the financial help to which they are entitled is surely an expression of Christian love.

There may be reticence on behalf of some pensioners to claim what is rightly theirs. There are other eligible pensioners who think the Pension Credit does not apply to them. Some will have previously been turned down for a benefit, and hesitate to apply again. Others may not realise how much they could receive as a result of applying for Pension Credit. Whatever the reason for not claiming Pension Credit so far, if there is a chance that a pensioner might be eligible, he or she should be encouraged to make a claim.

The only question remaining is how best to encourage pensioners to make a claim. When Cold Weather Payments were first introduced, it was not an automatic payment. So a church in south London to which many pensioners came one weekday afternoon for another purpose used the opportunity to encourage them to claim the new benefit. As a result of one afternoon’s work, hundreds of pounds were put into the pockets of local pensioners. The joy hard-pressed people experience when they receive extra money to which they are entitled (but about which they had previously been unaware) is wonderful to behold.
With the introduction of Pension Credit, churches have the opportunity to offer support to pensioners in their local communities by making Pension Credit known to them. With funding from the Lloyds TSB Foundation for England and Wales, the Christian Council on Ageing is able to provide a pack of publicity material to any church willing to use it.

The pack comprises:

- a poster (A3-size)
- an explanatory leaflet for church leaders
- a suggested article for a local church magazine or newsletter
- some small cards, giving the Pension Credit telephone number, for distribution to those who may be eligible to receive Pension Credit but have not yet applied.

The pack is available free from the Christian Council on Ageing, c/o Epworth House, Stuart Street, Derby, DE1 2EQ, or you can request a pack by sending an e-mail to roy.allison@bushinternet.com

We welcome contributions to this Newsletter. The copy date for the next issue is 8 May 2004.