

# Dementia Newsletter

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The Editor welcomes contributions and letters for publication in forthcoming issues.

## Chair's letter

Dear Friends

Anniversaries are a time to look both backwards and forwards, and this is the 50<sup>th</sup> edition of the Newsletter having been produced for the last 25 years.

25 years ago I had been working as chaplain to Westbury, MHA's first dementia care home, for just a year and still finding my feet. One of the voices that first encouraged me in my work among those living with dementia was Tom Kitwood from the Bradford Dementia Unit. His plea that we should hold the person at the centre was echoed a few years later by Malcolm Goldsmith who asked us to listen to what people with dementia were saying.

So what has changed in 25 years? Has care for those living with dementia changed from the institutional impersonal care that was common then to a person-centred approach? Maybe your answer would be that it depends, both on the organisation offering the care and, even more important, on the individual delivering care.

Just this week a neighbour has gone to live in a dementia care home and a friend is about to

spend all half-term week looking for a care home for her mother. Such hard decisions, which are often made without access to the information they need to make a fully informed choice. Education is the key. For while we do pray that medical science will offer some help, it does still seem a long way off. So we are left with the question of how we care.

This Newsletter offers bite-size snippets to gateways to a greater understanding of the possibilities as well as the difficulties. So please share it!

Anniversaries are also a time to say thank you to those who have worked so hard to collect and collate this Newsletter.

Margaret Goodall

## News

The University of Cambridge has been announced as one of the centres that will form the UK Dementia Research Institute (UK DRI) alongside Cardiff University, the University of Edinburgh, Imperial College London and King's College London. Director Professor Giovanna Mallucci comments 'Our centre on the Cambridge Biomedical Campus

will focus on interdisciplinary science, building on our University's strengths across research areas from chemistry and biophysics through to cell biology or neurodegeneration.' Mallucci announced on 16 May the outcome of research published in 'Brain' showing that two drugs had restored protein production rates in mice – trazodone hydrochloride, a licensed antidepressant, and dibenzoylmethane, a compound being trialled as an anti-cancer drug. Both drugs prevented the emergence of signs of brain cell damage in most of the prion-diseased mice and restored memory in the FTD mice. In both mouse models, the drugs reduced brain shrinkage which is a feature of neurodegenerative disease. She is hopeful that in 2-3 years' time they can be shown to be effective for persons with dementia.

A study by University College London published in early May, based upon data from the English Longitudinal Study of Ageing, forecast that more than 1.2 million are expected to be living with dementia by 2040 (up from almost 800,000 today). This will mean a great increase the cost of dementia to the UK economy from the present level of £23 billion.

Of particular concern to persons with dementia and their families has been The Care Quality Commission's report, following extensive unannounced visits of 4,000 care homes, that 32% had been rated inadequate or requiring improvement and that 37% had been told they must improve safety. Only one in 50 of all care services managed to achieve the top rating of 'outstanding'. Alzheimer's Society's Nicola O'Brien commented that their own investigation last year 'revealed people with dementia left in soiled sheets, or becoming ill after eating out-of-date food, and that only a third of homecare workers had received dementia training, leaving families fearing for their loved ones. We need to see the government act before the care system collapses.'

Data collected from 98% of GP practices by NHS digital and published in June showed that 422,000 people over the age of 65 were recorded as having dementia though many remain undiagnosed. It is most common in women aged 90 and over

A Public Health England report in July noted that since 2001 death rates from heart disease and stroke have halved for both males

and females whereas deaths from dementia have increased by 60% in males and have doubled in females. This is largely due to increased life expectancy and the current lack of effective treatments for dementia.

Two items on the BBC Today programme in mid-July are of great interest. On 15 July Dr Eric McDade spoke of Washington University Medical School's Diane Project which aims to study long-term those at high risk of dementia with a clear genetic link, treating them with currently two therapies in the hope that such early intervention might prevent the development of the disease, likening this to the use of statins to reduce the risk of stroke and heart disease. Interviewed on 18 July, Sir Michael Marmot, director of the UCL Institute of Health Equity, said that life expectancy in England and Wales was now levelling off, which could be linked with rising death rates from dementia. This in its turn could be the outcome of reduced government investment in the NHS and social care and appeared to be affecting disproportionately those in lower and middle wealth brackets.

A significant report was given on July 19 at the Alzheimer's

Association International Conference in London by the Lancet Commission on Dementia Prevention, Intervention & Care, co-authored by Prof Gill Livingston of UCL and Prof Paul Ballard of Exeter University, indicating that taking action throughout a person's life can reduce the risk by as much as 35%. The nine factors which can be modified by the individual are: mid-life hearing loss 9%, failing to complete secondary education 8%, smoking 5%, failing to seek early treatment for depression 4%, physical inactivity 3%, social isolation 2%, high blood pressure 2%, obesity 1%, type 2 diabetes 1%.: Even if only 5% of cases could be prevented by individuals taking appropriate action it would mean 5,000 fewer cases in Britain per year. The deafness and depression factors would seem to contribute to social isolation. Ballard says that there is much evidence that depression is associated with an increased risk of developing dementia but 'what we don't know is whether treating depression better prevents it'. The researchers say they did not have enough data to include dietary factors or alcohol in their calculations but believe both could be important. In effect the report examines the benefits of building a 'cognitive reserve', which

means strengthening the brain's networks so it can continue to function in later life despite accumulated damage.

A study published in the July issue of *The International Journal of Neuropsychopharmacology* suggests that a 'brain training' game developed by researchers at the University of Cambridge could help improve the memory of patients with amnesic mild cognitive impairment (aMCI) which has been described as the transitional stage between 'healthy ageing' and dementia. It is characterised by day-to-day memory difficulties and problems of motivation. At present, there are no approved drug treatments for the condition. The researchers randomly assigned forty-two patients with aMCI to either the cognitive training or control group. Participants in the cognitive training group played the memory game for a total of eight one-hour sessions over a four-week period; participants in the control group continued their clinic visits as usual. The game was played on iPads and challenged and incentivised participants to associate different geometric patterns with different locations. The results showed that patients

who played the game made around a third fewer errors, needed fewer trials and improved their memory score. Episodic memory is important for day-to-day activities and is used, for example, when remembering where we left our keys in the house or where we parked our car in a multi-story car park. Compared to the control group, the cognitive training group also retained more complex visual information after training and, importantly, enjoyed playing the game. Their confidence and subjective memory also increased.

Society Guardian on 26 July featured Admiral Nurses under the heading: 'A lifeline for carers that is all too rare'. Trained and supported by Dementia UK a total of 200 nurses (compared with 4,000 Macmillan cancer nurses) work in hospitals, hospices, care homes and in social care, but there are none in many counties, even though it is demonstrated that they save money through avoiding or delaying admissions to care homes and hospitals through the support they give to family carers, each nurse being responsible for 50-60 patients.

A study by a Newcastle university team headed by Prof Carol Jagger published in *The Lancet* in mid-

August predicted that there will be an additional 353,000 older people with complex care needs, including dementia, by 2025, necessitating an additional 71,000 care home spaces. Unless action is taken now, the continuing closure of care homes means that this target will be impossible to achieve.

Writing in the New Scientist on 14 September Anil Ananthaswamy described how by means of a new algorithm artificial intelligence can identify changes in the brains of people likely to get Alzheimer's disease almost a decade before doctors can diagnose the disease from symptoms alone. The technique uses non-invasive MRI scans to identify alterations in how regions of the brain are connected. An early diagnosis can also allow people to [start making lifestyle changes](#) to help slow the progression of the disease.

The Guardian published a Dementia Awareness supplement to coincide with World Alzheimer's Day on 21 September. Actress and singer Carey Mulligan, who is an Alzheimer's Society ambassador, wrote movingly of her Nan's dementia who continued to enjoy Carey's music. Other writers made it clear that volunteers, whether with or without dementia,

to take part in research, are welcome (contact [joindementiaresearch.nihr.ac.uk](mailto:joindementiaresearch.nihr.ac.uk)). Amy Little of Global Alzheimer's and Dementia Action Alliance shows how women worldwide not only face a greater prevalence of the condition but also shoulder the burden of care and face the greatest stigma.

Confirming the findings of earlier research in the field, a Chicago University five-year study of some three thousand people aged 57-85, published in the Journal of the American Geriatrics Society in late September, found an association between diminished ability to detect different odours and dementia. Professor Jayant Pinto commented that 'loss of the sense of smell is a strong signal that something has gone wrong and significant damage {to brain function} has been done and that a simple test could provide a quick and inexpensive way to identify those who are already at high risk'. However, Rosa Sancho of Alzheimer's Research UK, which is carrying out its own research in the field, points out that there are other reasons why people could lose their sense of smell.

## Reviews

**'Dementia: The One-Stop Guide'**  
**by June Andrews** (2015, Profile Books, London). 378 pages, paperback, £9.99, ISBN 978-1781251713

From the outside this book looks and feels like a cheaply produced publication with the slightly misleading subtitle 'Practical advice for families, professionals, and people living with dementia and Alzheimer's Disease' (my italics). Do not be misled. It is full of practical advice and information including the fact that Alzheimer's Disease is, of course, one form of dementia. Never judge a book by its cover, especially this one!

June Andrews was until April 2016 the Director of the well-established and highly regarded Dementia Services Development Centre at the University of Stirling, of which she is now an Emeritus Professor in recognition of her contribution to the field of dementia care. A former senior nurse and health service manager she writes out of a wealth of experience and knowledge but with a lightness of touch which makes this a very readable and useful companion for anyone, professional or lay, wanting to understand and support people living with dementia.

Starting with the basics Andrews describes some of the most common types of dementia and the role of diagnosis. Verbatim accounts from relatives and nursing staff illustrate the impact misunderstandings about dementia can have on the care provided to those living with dementia. The significance of non-verbal communication is dealt with in her inimitable style: "When professionals say 'She can't communicate', they really mean 'She can't communicate in a way that I can understand'. Verbal communication is not all it's cracked up to be. Ask any cat – they do fine without it."

As well as much very practical advice supported by real life stories there are several simple graphs illustrating very clearly the difference such advice can make from diagnosis onwards. The lower curve shows someone living with dementia going downhill fast whilst the higher curve demonstrates how, with appropriate actions, they could stay well as long as possible. For example, in trying to keep dementia at bay such actions include diet, exercise, socialising, avoiding hospital, environmental design, medication, sleep and alcohol and smoking. Both curves

share the same starting and end point but the journey has the potential to be a very different experience. Stress reduction can play an important role here, too, and the practice of mindfulness meditation is outlined as one useful approach. Suitable levels of heat and light at different times of day and night are further practical considerations. When it comes to alcohol Andrews rejoices at the research that seems to show some beneficial effects of a modest intake of champagne; personally, I prefer the University of Bordeaux's recommendation of red wine as a prophylactic.

Managing care at home is a major concern of many families and is given close attention here, as is the business of managing care during a hospital admission and choosing a care home. The complexities of health and social care systems are explored with useful illustrations of the frustrations and difficulties in negotiating a way through them. Whilst careful not to give definitive information about the legal status of such provision Andrews draws attention to some of the differences between the four countries of the UK and advises readers to check details closely.

She advises making a pot of tea and reaching for your reading glasses when it comes to attempting to complete some assessment forms with their many pages and abundant small print.

The dangers of a hospital admission are illustrated with another graph with the salutary warning that incidents such as fractured hips or urinary tract infections could be the fast track to a care home given the level of understanding of dementia in many acute hospital wards. The importance of the life story of the person living with dementia is stressed and well demonstrated by quotes from carers and workers. This makes the need for the practical advice offered throughout the book all the more real. A closing section on how best to make a complaint is followed by a comprehensive list of key agencies to which to turn for further advice, information and assistance.

The role of religious faiths, their communities and leaders is included on more than one occasion as potentially relevant for some folk amongst other sources of support.

While written in a warm, friendly and highly informative style this book does not disguise the many

challenges facing those living with dementia and their carers. This is an excellent practical guide which covers vital ground very effectively; it will benefit anyone concerned to improve the quality of dementia care.

Brian Allen (Newcastle upon Tyne)

***'Cries from the Heart' by Ann Jewell*** (2017, Millie's Foundation, Alderney). £5 plus £2 p&p (reduction in postage for bulk orders).

I was delighted to receive from Ann Jewell (who is not a relation of mine) a copy of her book, 'Cries from the Heart' which comprises 17 moving poems arising from her experiences in caring for her husband of 60 years who has dementia. It certainly shows that poetry is a better vehicle than prose for conveying the poignant and often contradictory emotions that arise as she wrestles with the dilemmas posed by seeking a diagnosis, making the decision to find residential care, signing a 'do not resuscitate' directive etc. The poems are Psalm-like in their honesty in regard to anger, grief, guilt and despair and will surely strike chords with other carers. Throughout she is sustained by the love that has always bonded them together, the cherished moments

when she is assured 'You are still you!', the prevailing metaphorical image of the butterfly and a questioning faith which, even when fading, yet leaves her 'strangely warmed'. The book is beautifully illustrated by Lindsey Scott, a carer in the home where Ann's husband is now resident. Profits from sales go to Milly's Foundation, Alderney's dementia charity.

Please order from: Eileen Mignot, 8 St Martins, Alderney, GY9 3UB. Email: eileen.mignot@cwgsy.ne

Albert Jewell

***'Thinking of You: a resource for the spiritual care of people with dementia' Joanna Collicutt*** (2017, BRF)

If I was to sum up this book in just a few words it would be to say, 'It's OK'. This is an affirmation that is definitely counter-cultural in our society which sees dementia in such negative terms. Collicutt offers reassurance that the person is not lost in dementia and offers thoughts for reflection and practical ideas in four inter-linked sections of the book: Thinking about Dementia, Thinking about the person with Dementia, Thinking of you: spiritual care for the person with dementia, and Thinking about us: dementia-friendly church.

Through Collicutt's expertise in both neuropsychology and pastoral care she gives insights into what happens in the brain and how dementia is a particular form of ageing of the brain that shows itself in cognitive decline. She reminds the reader that although the person is not 'ill', they do have a psychological disability so the person needs to be offered care, and that this care is not one dimensional but includes the biomedical, psychological, social and spiritual. A timely reminder that this complex condition demands complex care.

The four sections of the book are introduced and then link back to ideas already used. This allows the reader to make connections more easily and integrates the theoretical – both psychological and theological – with the practical. Practical suggestions include the use of Godly Play and Memory Books, as well as ideas for services and insights into the workings of care homes as well as what might be expected when taking a funeral.

The writing and language of the book is very accessible, and is helped by having the main points of each page highlighted in bold. The diagrams in the first section

offer another way of understanding what is going on in the brain.

One section which I especially found useful was the 3-fold approach to spiritual care: 1. Solidarity (I am with you) being present; 2. Hope (It can be different) making meaning; and 3. Identity (you are cherished), remembering the person. All of which leads to peace: It's OK. I cannot think of a better message to offer those living with dementia and their carers.

Margaret Goodall

## **Networking**

### **Faith in Older People, Edinburgh**

#### **Confidence and comfort in support of people experiencing dementia**

When our founder, Malcolm Goldsmith, set up Faith in Older People (FiOP) 12 years ago he wanted to share the experience of supporting older people in his congregation who felt they could no longer play a part in their congregation or in worship. He wanted to ensure that older people who were experiencing dementia or other conditions could still feel included and honoured.

In his book 'In a Strange Land – People with Dementia and the Local Church' he set a challenge which has underpinned much of the work that has been undertaken by FiOP since its inception: 'To face up to the presence of dementia within our midst is to discover opportunities for service and growth that are entirely consistent with the church's distinctive mission and role within society. To ignore that challenge is to raise serious questions, not only about our understanding of what it means to be a church, but also about our understanding of what it means to be human. To ignore that challenge must raise questions about our understanding of the importance of the spiritual dimension to the life and to the lives of countless people, many of whom would be included in "these the least of my brethren"'.

Although society is much more aware of dementia and the impact it has on individuals, families and friends we know that people with dementia and their carers often self-exclude themselves from church and other activities because they don't want to be or felt to be a nuisance. But it is just as frequent to observe that other members of the congregation don't

know how to react to someone with dementia, feel pity rather than empathy and then tend to ignore those in this position. We need to do so much more to communicate and to create confidence on all sides to ensure that our churches remain inclusive and welcoming. We need to avoid the heartache experienced when no one talks to your mother at coffee anymore because of a lack of understanding and feeling able to treat someone the same way that they have for the past 20 years.

FiOP is very aware of the tremendous work that has been undertaken by the Methodist Church, Livability, the Church of Scotland and other churches to increase understanding and to provide practical information. In developing our work FiOP has built on this strong basis to draw up a toolkit which encourages congregations to consider where they are in supporting people with dementia encompassing understanding what dementia means; how suitable are the buildings; how aware are people of the supportive resources in the community; and is worship inclusive.

In developing this approach, we want to consult with congregations

to encourage people to see how adaptive their congregation is and what more they need or want to do. The intention is to be affirmative and enabling drawing on the capacity of everyone to ensure the church is inclusive. To date we have presented to a variety of congregations and Presbyteries, held workshops and produced information. We have an active working group and are privileged to have the project led by Professor Mary Marshall and Jenny Henderson who bring such a wealth of experience with them.

This project is running in tandem with one we are developing in care homes. We are very conscious that faith plays a significant role in the lives of many older people and it is important to ensure that they have opportunities to continue worship and the chance to keep their connections with a church. So, whilst we are both encouraging and supporting people within congregations to better understand dementia and continuing connections, we also need to ensure that care home staff understand the range of spiritual care needs of residents and to be welcoming to local churches as the residents would wish.

A programme is being piloted in care homes to demonstrate a way in which care home staff can engage with their residents with dementia to identify their spiritual needs and how they might be effectively met. This is fundamental to good person-centred care which should bring together the physical, social, psychological and spiritual dimensions. It is important to create opportunities to enhance the experience of people with dementia so that their capacity is maintained, even for a short while, through ritual, rhythms, music and touch. We are encouraging the formation of an attentive group for an individual which includes those who love and support them.

This is not always easy given the competing demands on the time of care home staff but it does not rely only on staff but draws in family, friends and others to have a clear activity in which they can join with a resident. It can create new channels of understanding as well as building relationships with relatives who often also struggle with the situation.

Building confidence, comfort and creativity is at the heart of what we are trying to achieve.

Maureen O'Neill, Director, Faith in Older People

[www.faithinolderpeople.org.uk](http://www.faithinolderpeople.org.uk)

## Reference

Malcolm Goldsmith, 'In a Strange Land – People with Dementia and the Local Church. (2004) 4M Publications.

### **Dementia: How should we care for the carers? Report to the churches.**

The campaign that all sections of society should become more 'dementia friendly' has clearly been gaining momentum in recent months. But the question remains: Are we paying enough attention to the needs of those who care day by day for loved-ones with dementia?

In a recent study, 53 churchgoing carers across the denominations, two-thirds of whom were female, agreed to answer questions about their experience caring for someone very close to them who was suffering from dementia. Their responses were heart-felt and deeply moving. They challenge churches and other agencies to consider much more carefully how best to address their needs in what is clearly an emotionally draining and very lonely role.

### *The unique challenge of caring for a loved one with dementia*

Inevitably, since dementia occurs mostly amongst older people, the responsibility for care tends to fall on family members who are themselves older. 42 of the 53 respondents in this study were spouses, 8 were daughters or sons. None was less than 50 years old; most were in their 70s and 80s.

Since dementia is a long, slow and progressive disease, often leading to unpredictable and unwelcome behavioural changes, the burden of care is relentless and tears at the carer's emotions. In this study, most respondents had been caring for their loved one for more than three years. For two the role had lasted more than 20 years. One daughter was still caring for her mother after 17 years.

It is clear from the responses that such caring presents a unique combination of challenges: Alongside the tiredness and emotional stress of non-stop caring over a long period of time, respondents highlighted three main factors: 1. Most significant were the changes in their relationship with their loved one, the lack of normal patterns of communication as the dementia became more pronounced. Some

likened it to bereavement. They had lost the one in whom they confided most. 2. Many also mourned the loss of the social contact they had previously enjoyed, in church or elsewhere, as others found the dementia too difficult to deal with. 3. There were patchy levels of understanding of carers' circumstances shown by medical, social and welfare services, and by church leaders. Cumulatively, almost all carers in this survey revealed significant degrees of loneliness, alongside grief, guilt, anger and, in a few cases, something close to clinical depression.

#### *The diverse ways of experiencing a supportive faith*

As regular churchgoers, this study's respondents brought to their caring role their faith as Christians. Almost all reported that, despite the all-encompassing pressures of their caring role, their faith had been supportive and had helped them to cope. However, their responses revealed two quite distinct ways of expressing their relationship with God through faith: For just over half of these churchgoing carers, God was their rock. Their faith in God was 'static', 'unshakeable'. At the very least – despite all the pain they were

experiencing – their faith 'survived'. For the rest, their faith was a journey in which they discovered how God was empowering them to cope. Their experience of God was 'dynamic'. 'God's grace was sufficient for them'. As a result they spoke of their faith being challenged, but also 'deepened'. Just one suggested that her faith had been 'lessened', commenting "It is hard to continue to believe in the power of prayer when you are dealing with an Alzheimer's sufferer."

By focusing on people who saw themselves as churchgoers, this study failed to reach those who, as a result of their caring experience, had lost their faith and totally ceased churchgoing. In practice, for many carers in this study, continued churchgoing clearly became progressively more difficult over time, and for some the return to regular churchgoing was also proving quite difficult after their caring role had ceased. Their faith, however, clearly remained central in their lives.

#### *Taking older people seriously – as individuals*

Most respondents described some degree of support from their church, practical, pastoral or through prayer. However, many

pleaded for a deeper understanding both of dementia and of what they were enduring as carers. In this study, what care-givers most prized was to be understood and empowered to cope with their responsibilities for as long as possible. Many said that they were unwilling to ask for help. Caring for their loved one was their responsibility – even their privilege. Could they really trust anyone else to care for that person as lovingly as they did?

However, despite the widespread loneliness, several respondents spoke warmly of new and deeper friendships, both inside and outside the churches – friends who could empathise and in whom they could confide. Although being enabled to join a group with other dementia carers was recognised as welcome and valuable, the deepest experiences of emotional loneliness could only be offset by more intimate one to one relationships between individuals.

#### *Some possible lessons for other churchgoers and church leaders*

One clear message from this study is that churches and churchgoers need to be less wary of those suffering from dementia, and learn how to avoid stigmatising and insensitivity. This will be easier if,

at the same time, we become more aware of the challenges facing the carer and of the individual circumstances and needs of the person with dementia.

Local churches can also plan explicitly to become more 'dementia friendly' – and realise that this is costly in terms of time and patience - and very demanding spiritually. Help is available to make this happen.

More generally this study reveals the unique qualities of an individual's faith journey over the course of a lifetime. Churches need to become better equipped to understand and respond to this - whatever may be that individual's personal circumstances and not least when they are older. It is unhelpful to try to impose prescriptive interpretations of what that faith journey 'ought' to be.

At a practical level, responses to this study show that many local churches need to be more disciplined about their pastoral care - and not leave it all to the minister! There is scope for more and deeper listening. Local church members should not give up on visiting those who are in danger of losing touch with their church because of the demands of their caring role.

However, more practical support and improved pastoral care, although necessary, may not be enough. Churches may have a crucial role in helping all carers, particularly those caring for loved ones with dementia, to find the new and deeper friendships that they need to offset the emotional loneliness of their caring role.

More specifically, some carers clearly face considerable difficulties, once their caring role has ceased, in returning to regular churchgoing after what has often been a long period of enforced absence. If other church members understand, they will be able to help.

Overall, churches need to recognise and respect what others outside their circle can do and are doing. All of us are challenged not to fear dementia, but rather to develop 'dementia-friendly' values, policies and practices in all our dealings with persons with dementia and their carers.

A full analysis of the responses to this study is presented in two academic papers:

Jewell, A., Cole, J., Rolph J., & Rolph, P. (2016). *The faith of primary carers of persons with dementia*. Journal of Religion,

Spirituality and Aging, 28, 313-337. doi:10.1080/15528030.2016.1193098

Jewell, A., Cole, J., Rolph J., & Rolph, P. (2017). *The loneliness of the long distance-carer: The experience of primary carers of loved-ones with dementia*. Rural Theology, 15, 2, 97-112. doi: 10.1080/14704994.2017.1375473

Useful resources for local churches:

<https://www.livability.org.uk> - the web site of the Christian disabilities charity Livability.

<http://www.christiansonageing.org.uk> - the web site of The Christian Council on Ageing (CCOA)

'Growing Dementia-Friendly Churches' by Gaynor Hammond – obtainable via the CCOA web site, price £6 inclusive of p & p

<https://www.alzheimers.org.uk> – the web site of Alzheimer's UK, where you can find details of your local branch of the Alzheimer's Society.