

Christian Council on Ageing Dementia Group

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Editorial Address

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New in time for Christmas!

O Tidings of Comfort and Joy

Favourite Christmas hymns sung by choirs and members of churches at Holy Corner, Edinburgh. CD price £5.00 (plus £1.00 postage and packing). Phone 01786 467740 or e-mail dementia@stir.ac.uk

From the Chair

As I sit at my computer trying to finish all pending work prior to a week in the south of France I experience a sense of déjà-vu. The issues in the public eye include several that have been around for a while without resolution or clarity.

The Joffe bill on assisted dying continues to arouse debate – we have written about it in previous issues of this newsletter. The much debated Mental Capacity Bill has been passed but little attention seems to have been given to it – other world events grabbed the limelight. More immediately, NICE still keeps us in

suspense with regard to anti-dementia drugs. The 'not cost effective' tag seems to have echoes in other settings where elderly people, especially those with dementia, are concerned.

When we think of palliative care, we often think of cancer care and occasionally extend it to conditions such as multiple sclerosis and other neurological conditions. However the speakers at a conference on Palliative Care in Dementia which I recently chaired at the Leveson Centre made it clear that dementia is a terminal illness and in its terminal stages warrants just as much attention to palliative care.

I was therefore heartened today when I opened the most recent issue of *Old Age Psychiatrist* (the Newsletter of the Faculty of the Psychiatry of Old Age of the Royal College of Psychiatrists) to find two pages devoted to terminal care. The article was written by two trainees in psychiatry who quote from one John Hinton (not referenced): 'The dissatisfied dead cannot noise abroad the negligence they have experienced.' They draw attention to the obligation to facilitate a good death in the Human Rights Act 1998 though they agree that a 'good death' is difficult to define. As an attempt to help in this situation they propose for dementia a modification of the Liverpool Care Pathway for the dying patient which was devised particularly for patients with end-stage cancer. One particular aspect of care of the patients in the unit they studied was the continued use of non-essential medication and I welcome their suggestion that following multi-professional collaboration all non-essential medication and investigations should be stopped. Care, as in all traditional palliative care, concentrates on relief of symptoms. Suggestions are made as to the most likely symptoms and possible ways of relieving them. I congratulate them on this work. I hope that those not convinced of the need for palliative care in end-stage dementia, wherever it is provided, will be prompted to think again.

As a final comment, I recently received a letter from a patient's daughter. I had seen her mother about four weeks earlier when, after a long discussion with the daughter, the manager of the care home, and some conversation with the patient, we agreed that she

was terminally ill. We decided that investigations into her sudden deterioration (clinically a further 'step' in her vascular dementia) and reluctance to eat would involve hospital and investigations which would distress her and would be unlikely to change the course of the illness. Tube feeding seemed cruel and inappropriate. The residential home staff were prepared to continue to care for her as long as possible. She died among friends, family and in a comfortable and familiar environment. Surely a 'good death'.

Spiritual care takes many forms. Care of the dying seems one context where it is still seen as relevant by most people. We need to ensure that spiritual needs are met wherever and whenever there is life.

Reference: R A Siddiquee and S Deshpande (2005) 'Care Pathway for the dying patient with dementia', *Old Age Psychiatrist*, Royal College of Psychiatrists, Issue 40, 10–11.

Daphne Wallace

Forthcoming Events

3 November *Perspectives on dementia care* University of East Anglia Norwich. Speakers include Professors Joanna Bornat, Jill Manthorpe and Clive Ballard and carer Barbara Pointon. For details phone 01603 261951 or e-mail jackie@wolvercott.co.uk

15 November *A good funeral* Speakers Dr Tony Walter, Richard Bragg, Dr Janet Eldred, Revd Mark Pryce. For details phone 01564 778022 or e-mail leveson.centre@virgin.net

Recent events

Report on 'Lighting the Way: meeting the spiritual and religious needs of people with dementia' held in Carshalton on Wednesday 27 April 2005

My initial thought on seeing the advert for this conference was 'Now this is a step forward, at long last!' – secular groups getting

together in partnership with faith groups represented by the various chaplains. I was intrigued to see what the day would unfold not least because for so long most of the expertise, research and development of spiritual care of those suffering with dementia has been mainly concentrated north of the Watford Gap. This has been a real drawback to getting initiatives off the ground in the south.

The initial opening remarks led onto the powerful videoed report about the Revd Joy Moy who shared with us the very personal experiences of someone in the early stages of dementia, not least her struggle as she came to terms with the disease and the spiritual demands it was making on her. It left the conference deeply moved and raised a number of significant questions about the particular spiritual support that people like Joy needed – for example another member of the clergy who would act as a soul friend on her ‘journey’ but who would be completely au fait with the disease and its conundrums.

A question as to the availability of the video gave rise to the hope that copies would be available in the future but as of date I have no news of its production. The general view of the 100+ delegates present was that it would provide a very valuable training and raising awareness resource.

The day continued with a chance to view the displays and resources available over coffee and lunch and a number of workshops and opportunities to catch up on the news and developments elsewhere. One of the delights of the day for me was that a significant number of people attending were from a wider area than just the local NHS Trust catchment area – for example delegates came from Canterbury, Maidstone, the Midlands and even as far as Edinburgh.

We learnt about The Candlelight Group and a publication about how the Group developed was available for all attending (see below for a review).

Other workshops looked at designing acts of worship for those with dementia, what is dementia, the spirituality of caring and multi faith-questions. These latter two were of interest to me in respect of my hoped-for Dementia and Spirituality Special Interest group which at that time was very much in its conception stage. It was reassuring to hear that others are also exploring the issues of provision of spiritual and religious care in a multi-faith context as our planned network in the Kent-based DSDC area (Kent, Sussex and Surrey) is also to be multi-faith.

The day concluded with an Assistant Curate based in a Battersea parish sharing her thoughts as experienced from the viewpoint of a priest and previously as a nurse who rose to the post of Chief Nursing Officer for England. It made interesting listening not least because there is still a tension between the physical and mental needs of those being cared for and the now acknowledged need to refocus on how the workforce can meet the spiritual needs of patients.

The oft-heard phrases of National Service Framework conditions, good practice models, independent living, care planned around needs and choices were included in this professional presentation but it did take that hoped-for extra step in voicing the need for more training for staff on the spiritual needs of patients and how we can enable people to recognise their own spiritual needs. Revd Sarah Mullally went on to stress that there needed to be collaboration across the boundaries that exist in the care professions and that this posed a challenge to us all, not least church leaders and that all the multi-staged developments were set against a youth-oriented secular society.

It was stressed that although the numbers of chaplains had increased over the last ten years, there were still not enough to go around especially with the overarching requirement to treat all patients/clients as individuals. And so we came back to the underlying need to raise awareness through education and thus gain a larger workforce tuned into all the needs of those in their care, including their spiritual needs.

I found the day very affirming and uplifting and it confirmed my thoughts on the need for enhanced development in raising awareness generally on the care provision for those suffering from dementia and especially from my perspective the vital need of spiritual care.

The increasing interest in dementia demonstrated at that day conference and subsequent events such as the recent launch of the South East Dementia Services Collaborative (a 150-place sell out!) all strongly indicate that maybe at last all the various agencies – statutory and voluntary – plus the faith groups are now merging to work in closer partnership and thus increase the focus given to rights and care due to those suffering from dementia. And this includes their spiritual needs!

A final quote of Joy Moy's from the video, which perhaps is the most poignant from the day:

'Jesus is grieving for the part of me that's missing (my brain) and I am too. I am putting my trust back to Jesus, my friend and brother but also in God my Father who is not going to let any harm come to me.'

Dot Hooker (Older People's Advocate and Steering group member of DemSSIG, Dementia and Spirituality Special Interest Group)

Palliative care for people with dementia – a seminar held at the Leveson Centre on Wednesday 7 September 2005

I had never been to the Leveson Centre before. What a fantastic building and it seemed so fitting to have a seminar on palliative care for people with dementia there. The building somehow invited the subject. However I know that in the current world, people with dementia don't always receive their palliative care or end-of-life care in such a lovely environment or in receipt of the strived-for ideals put forward during the seminar.

The importance of good holistic palliative care, truly centred on the needs and wishes of the person, is something everyone

should strive to achieve in the support of a person on their final journey. Once a person knows/feels they are in that final stage, then care becomes palliative no matter how long that journey might take. As the seminar recognised, many think of cancer when palliative care is mentioned. There is nothing wrong with that. But palliative care for people with dementia? Just because a person has dementia does not mean that the need for good palliative care should not exist – quite the contrary. A diagnosis of dementia means palliative care should start immediately. Dementia means ongoing loss and bereavement for all involved and can be even worse because the person concerned is unable to rationalise and understand as they could before their dementia. A person with dementia often has physical complications too. Dementia therefore means a double or even triple whammy of fear and insecurity for both for the person and their carers. All the more reason to give good palliative care as well as good end-of-life care! I was full of positive anticipation especially as I have been involved personally in the palliative and end of life care of a person with dementia, and because I work in a professional capacity with people with dementia and their carers.

I immediately warmed to Dr Daphne Wallace, Chair for the day and I felt this every time she spoke. What a wonderful lady! How good it would be to have her on side if you had dementia or if you were a carer. She was warm, down to earth, knowledgeable and realistic and I am sure, not afraid to give the added whoomph that a consultant can so often do for the benefit of the person with dementia. I couldn't help but wish she had been the consultant when I was a carer.

Dr Katherine Froggatt, I thought, spoke a lot of sense. We need the practically experienced, 'scientists', to research and make palliative care for people with dementia better. We need the practically experienced lecturers to deliver the message on how to do this, to those cross boundary workers just starting out and to those already in the field of dementia care. We need to know the theory in order to produce the good practice. I felt Dr Froggatt presented her subject well with the important recognition that the feelings of the carers matter too – carers need support to accompany their loved one on that final journey.

What a breath of fresh air Dr Adrian Treloar was, presenting his subject with a superb dry sense of humour but also demonstrating the great sensitivity he had to the needs of his terminally ill mother-in-law, and also to his wife and children all at the same time as going through another huge and personal loss. I thought he was a true example of a person turning a negative situation into a positive one with the determination to provide good palliative care where a person most frequently wants to be – at home and alongside the people that know and love you. This would have been such hard work not just emotionally but also practically in getting the resources necessary to care. However, he managed to portray the rewards of doing this, demonstrating to us how much better his mother-in-law was both physically and mentally than when she was in residential care. He showed us that palliative care for a person with dementia, although difficult and stressful can be so rewarding and worthwhile.

With plenty of food for thought, we went into food of a different kind – lunch. For me, lunch was wonderful. I received true person-centred care with the provision of a gluten-free meal.

After lunch Revd Margaret Goodall gave an excellent presentation about palliative care in a residential setting. She made some important points and said all the right things – all the things that we should be striving for if a person with dementia has to receive palliative care in a care home setting. She recognised too that there are problems in ensuring good palliative care in some homes and even recognised that people with dementia would be better at home, close to people they love. I shared many of the ideals Margaret stated as I felt many of the attendees did, but I know realistically from what carers and people with dementia tell me in the course of my work, that good palliative care does not happen in the majority of care homes even though people will tell you it does. Indeed on a personal level too, I have seen some questionable palliative and end-of-life care for people with dementia, mostly as a result of ignorance and poor training and a basic lack of thought and common sense. I could not help but feel that deep down there was an element of rather serene care home ‘promotion,’ going on.

With the final speaker, I was really hoping for a broader outlook on palliative care in hospital. We had a good powerful speaker in Leslie Dinning who spoke about end-of-life care rather than true palliative care and from a wholly religious and chaplaincy viewpoint. The speaker obviously carries out very important and valued work with people with dementia that is so necessary, and also very comforting and there is a definite place for this. However, there are people with dementia and carers who do not want a minister or chaplain. What happens to their palliative care/end-of-life care? In my view, as with care homes, hospitals also have a long way to go in understanding how to provide good palliative and end-of-life care for people with dementia and I think there has to be a total rethink here. What about real patient choice because people with dementia can still make real choices albeit in their particular way during their final stages, in some cases even up to the point of dying.

Certainly a thought-provoking and stimulating day!

Fiona Bassett (Derby Branch of the Alzheimer's Society)

News

The Guardian recognises the spiritual needs of people with dementia

It was encouraging to note that in a *Guardian* article (26 April 2005) about Christine Bryden's book (see review in the April Newsletter, page 10), a list of hints entitled 'How to cope with dementia' includes: 'Look towards the spiritual (not necessarily religious). Think what you would do – or the person with dementia – might do if you had an hour a week just to be. Listen to music, enjoy nature, stroke the cat? That may be your spiritual.'

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PhD thesis

Congratulations to Wendy Hulko who has gained her PhD at the University of Stirling with a thesis 'Dementia and Intersectionality: exploring the experiences of older people with dementia and their significant others'. It is good to know that work is being done on the effects of a diagnosis of dementia on family and friends.

Quality Research in Dementia (QRD) Advisory Group

The QRD Advisory Group urgently needs new members. This is a group of carers, ex-carers and people with dementia who are asked to evaluate and categorise all the research proposals that come to the Alzheimer's Society for consideration for research grants. Training is provided and expenses for travel and meetings paid and members can attend the AGM of the Society free of charge. For further details e-mail research@alzheimers.org.uk or phone 020 7306 0606.

Retirement of Professor Mary Marshall OBE

Professor Mary Marshall retired from the Dementia Services Development Centre in Stirling at the end of August. There have been many tributes paid to her and the *Journal of Dementia Care* (September/October 2005) devoted three pages to an evaluation of her contribution and influence. She was a tireless advocate for people with dementia and the work she initiated at Stirling has now been replicated in a network of centres in the UK as well as the Hammond Care Group's centre in Sydney, Australia. The CCOA Dementia Group would like to add its thanks to Mary for the inspiration and friendship shown to so many of us.

Activity and dementia

A report from Alzheimer Scotland raised concerns over the well-being of people with dementia in care homes. A survey found that many are being inappropriately prescribed antipsychotic drugs and that on average they spend only 3% of their day doing

constructive activities. It recommends that 'activities should be led by an activity worker, be dementia friendly and reflect individual interests, abilities and spiritual needs.' See www.alzscot.org for the full report, *This is my home: quality of care for people with dementia living in care homes*.

NICE decision on dementia drugs

There was widespread anger at NICE's decision to gather more evidence before deciding whether to withdraw dementia drugs. It plans to ask pharmaceutical companies to research whether the drugs are particularly effective for certain groups of people. An alliance of leading charitable and professional organisations in dementia care and research has been launched in an attempt to ensure that the voices of people with dementia, their carers and health professionals are not ignored in the next stage of NICE's deliberations. A further statement is now expected in December or January.

Website for people with dementia

West Kent branch of the Alzheimer's Society has won an award for its new website specifically for people with dementia, called the Alzheimer's Forum. One of its objectives is to enable people with dementia to communicate with one another and write about their personal experiences. See www.alzheimersforum.org

Singing for the Brain

An article in the October 2005 edition of *Share*, the journal of the Alzheimer's Society, describes a group in West Berkshire called 'Singing for the Brain' which uses rhythmic work and singing to give people with dementia and their carers an opportunity of sharing a pleasurable experience together. A keen supporter of the group Dr Nicholas Bannan, a lecturer in music education at Reading University, has carried out some research into participant's responses and found that even though formal language skills can appear lost the musical impulse is still present.

Many members of the Dementia Group will have personal experience of this through seeing people with seemingly little language joining in hymn singing. It is clear that using music with people with dementia is an area in which we can minister to their spiritual needs even when the disease is well advanced.

The Archbishop of Canterbury

Rowan Williams spoke on the theme 'The gifts reserved for age: perceptions of the elderly' at the AGM of the charity Friends of the Elderly. He attempted to counter views that 'being old is being dispensable' or that it is a 'stage of life when you exist on sufferance'. He spoke of the challenge of respecting and loving those with dementia 'who may seem to have no clear picture of themselves or others at all'. He suggested that how we treat them is 'as clear an index of our social vision as is the issue of how we treat children – almost more so, since these are not people who will grow and change in obviously positive ways.' He then asked the question, 'Are we truly committed to giving place and respect to those who can return nothing (as it seems)?' Speaking of his mother he referred to 'the feeling in the last months of her life that she was still struggling to communicate, to make some sort of sense; I couldn't understand or help, but I knew that at the very least I owed her my presence and my efforts to listen.'

He also expressed concern that the drift towards accepting assisted suicide and euthanasia could foster an attitude that resources spent on older people are a luxury we can ill afford.

For the full speech see www.archbishopofcanterbury.org/sermons_speeches/050906.htm

CCOA Dementia Group publications

Now available at only £2.50!

Religious Practice and People with Dementia was edited by a member of the Dementia Group, Revd Brian Allen, Chaplaincy

Team Leader of the Newcastle, North Tyneside and Northumberland Mental Health NHS Trust. Underpinned by the belief that addressing spiritual needs is essential to good all round care and that religious belief and practice is for some people a vital part of their spirituality, the booklet contains some basic introductory background information for five world faiths (including Christianity) followed by a brief selection of prayers and readings from each faith which carers might be able to use with people with dementia, or others for whom they are caring.

Copies of this and the following earlier publications are available from CCOA Publications, 19 Eldred Road, Liverpool, L16 8NZ enclosing a cheque payable to CCOA.

- DG1 *Newcastle Project Practice Guide*, £6.00
- DG2 *Video: Is Anyone There?* £15.00 including two booklets
- DG3 *Spiritual Care: Guidelines for Care Plans*, £2.50
- DG4 *Frequently Asked Questions on Spirituality and Religion*, £1.00
- DG5 *Religious Practice and People with Dementia*, £2.50

Also available from the address at the top of this Newsletter or free by e-mail from alison.johnson@clara.co.uk are:

- Dementia and Spirituality: an introductory reading list*, £2.00
- Dementia and Spirituality: an annotated bibliography*, £3.00

Recent publications

Notices

The Simplicity of Dementia: a guide for family and carers, Huub Buikssen, Jessica Kingsley Publications, 2005, ISBN 1-84310-321-4, £13.95.

This book is written with non-professionals in mind, to provide advice and guidance for relatives, carers and professionals working with people with dementia. There are summaries at the end of each chapter, tips on responding to aggression with a

focus on trying to prevent situations occurring. He also addresses sensitively the hidden victims of dementia – the family.

Working with Older People: a resource directory for churches

This Directory bringing together details of over 100 church-related organisations working with older people and listing many exciting projects across the country, including details of people working specifically with those with dementia, is now available for only £7.50 in a plastic wallet. For copies please send a cheque payable to The Foundation of Lady Katherine Leveson to Temple House, Fen End Road, Temple Balsall, Knowle, Solihull, B93 0AN or order on the website www.levesoncentre.org.uk

Reviews

Alzheimer: a journey together, Frederica Caracciolo, Jessica Kingsley Publications, 2006, ISBN 1-84310-408-3, 108 pages, £8.99.

When asked to review this book I did so with mixed feelings. This was partly because there has been such a plethora of similar publications lately, including the writings of Christine Bryden, and partly because people's experience of Alzheimer's is so varied. However, I have to report that Frederica Caracciolo's book is something special. The writing is beautifully done at both the descriptive and the emotional levels, the Egyptian-born Italian author being an accomplished linguist working with the UN. At only a hundred pages of text, it is not a word too long.

Caracciolo is well aware that how people cope with dementia, whether in themselves or in their loved ones, will vary according to their personality and situation; nonetheless she chronicles in poignant detail most of the frequently experienced staging-posts on this harrowing journey. She vividly portrays the loss of memory, verbal and other basic skills, the frustration, temporal and spatial disorientation (particularly distressing in someone who was an accomplished architect and designer), the restless-

ness, increasing physical frailty and yet preternatural strength, the constant mislaying and hiding of items, obsessions, momentary flashes of intelligence, recognition and joy, eating difficulties, incontinence – and so much else in the inexorably shrinking world of the person with Alzheimer's where the future seems to contain only dead-ends. In her husband Francesco's case this also extended to paranoia, hallucinations and epilepsy. Hardest of all to bear was that her husband no longer recognised Frederica as his wife though he continued to see her as 'a familiar and reassuring presence'. Equally clearly represented is the denial, impatience, continual anxiety, shame, sense of guilt and betrayal, and the sheer loneliness of the caring spouse, as friends and visitors ceased to call, collapsing into a total void and utter exhaustion after Francesco died.

There is much we can learn from this book about coping strategies. Keeping to a regular routine, encouraging the person with Alzheimer's to go on doing what they can (in Francesco's case taking cuttings of plants), taking out an enduring power of attorney before it is too late, the use of photographs from their extensive travels in Central Africa, the playing of favourite music, constant holding of hands, making the most of the present moment, and an ingenious adaptation of Francesco's bathing arrangements, all play their part. Frederica is aware of the vital need for her own bolt-hole (in her case her little study) where for a short while she could be herself again. Throughout she is acutely sensitive to the need above all to protect her husband's dignity. She comments early in the book that she felt she faced the daunting task of 're-inventing' Francesco's life; later she becomes aware of the dangers attached to this course: she needed to value him for what he had been and for who he still was.

Above all, this is a love story – with a difference. It was a love that blossomed through giving rather than receiving, reciprocal but expecting nothing in return. Similar, it might be said, to the tenderness felt towards a totally dependent child: 'It was perhaps the purest expression of love.' The penultimate chapter ends with these words: 'I realised that, in the end, our journey together

instead of a grievous duty had turned into a love story.' Thus did the author draw meaning and purpose out of suffering and now she remains a valued member of the Alzheimer's support group attached to the Sant' Eugenio hospital in Rome, continuing to find some sense in Francesco's sufferings and 'in helping them, I am making him live a little longer beside me.'

I would want to add two further comments. First, that Frederica evidently faced similar problems in Italy to those encountered by family carers the world over: little understanding, few statutory resources and the knowledge that essentially you are on your own. The other is that the author was surely fortunate in being relatively rich, so that full-time care assistance could be provided at home. Institutional care, not always of the most enlightened kind, may remain the only option for those who are less well-off. This being said, we can be truly grateful for this honest, poignant and insightful book which offers real encouragement to those many struggling with Alzheimer's today.

Revd Albert Jewell (formerly Pastoral Director, MHA and a member of the CCOA Executive and Dementia Group)

Lighting the Way: spiritual and religious care for those with dementia, Patricia Higgins and Richard Allen, South West London and St George's Mental Health NHS Trust, 2005, 52 pages, Free by sending an A5 SAE with a 46p stamp from Patricia Higgins, 122 Park Lane, Wallington, Surrey SM6 0TL.

The authors of this booklet, together with Alix Morgan, received the annual Award for Excellence and Innovation in Dementia Care, sponsored by the Alzheimer's Society and the Queens Nursing Institute for their work in setting up and developing the Candlelight Group which responds to the spiritual and religious needs of patients in the Downs Day Hospital by providing a weekly act of worship.

The booklet, funded from the prize, begins by reflecting on dementia itself and on the pastoral, spiritual and religious needs

of people with dementia. It then moves on to issues of worship with such a group and offers a set of principles to be followed when planning a service of worship. It looks at thirteen practical considerations to be taken into account ranging from the space, aspects of liturgy, music and symbols to problems of communication. A short section considers the application of their philosophy to other faiths.

The second half of the booklet headed Resources gives a reading, hymn or song and ideas for a time of reflection for every week of the year following the Revised Common Lectionary and an Appendix provides the complete service outline for the Candlelight group and services for Christmas, Easter and Harvest.

I can wholeheartedly recommend this booklet which would be invaluable to anyone involved in worship for people with dementia, whatever the setting, and the authors are to be congratulated on the comprehensiveness, clarity of expression and common sense of this publication.

Alison M Johnson (Secretary and Editor of the CCOA Dementia Group)

Website

The CCOA Dementia Group website continues, for the time being, to be hosted by the Leveson Centre for the Study of Ageing, Spirituality and Social Policy. A direct link to the recently updated site can be made by typing into your search engine <http://rps.gn.apc.org/leveson/resources/study-ccoa.htm>

We welcome contributions to the next issue of this Newsletter which should be in the hands of the Editor by 1 April 2006.

The influence of chronic disease on enduring relationships

Thierry Collaud is a Swiss doctor who is also a philosopher and theologian. The following is a condensed version of a paper he gave on 4 August 2005 at the 57th Conference of the International Group of Médecine de la Personne in Durham.

Introduction

My father died recently. He had suffered for many months from a multi-system disease with severe breathing difficulties. Looking at it from the perspective of personal autonomy, one could imagine that Leon Collaud's illness concerned only himself as the principal actor. He alone would have to reorganise his life, within the limitations imposed on him by his illness. As a general practitioner I would often call the patient only into my office, leaving his wife in the waiting room. Are our illnesses personal events concerning each of us individually or do they also influence those who share our lives?

The way my father lived through his illness cannot be considered only as his concern. Indeed he used to speak little of himself and of his deep feelings. Consequently I know only partly how he lived through the decline of his physical strengths, the anguish of increasingly difficult breathing and his approaching death. Part of his illness belongs to him alone forever. It is something that each of us in the depth of our soul, whether we are reserved or talkative, can never convey totally to anybody else, no matter how close we are to them.

My father's illness and his death affected and worried us all, saddened and modified our whole family. We lived through the evolution of this illness as something that was happening to the whole family and that crossed boundaries of differing degrees of relationship.

The illness imposed a reorganisation on the family, changing familiar roles. For example, my father tended his garden with

devotion. Latterly my mother took on that role so that the garden would live on, although I had never before seen her gardening.

For years my parents were part of my life without my ever wondering about the future. They were simply there, my personal reference, elements of stability for me; it was as though things would always be this way. Suddenly life appeared fragile: the possibility that what had been (and my father had always been here for me) would be no longer. The crisis of sickness is always a family crisis. The family bears the suffering with the sick person but at the same time can be a source of strength and resource for life in a new context marked by fragility and vulnerability.

We are never alone

We are shocked to read in the newspaper of somebody found dead more than a year after the death. Such loneliness seems abnormal and inhuman. 'It is not good for a man to be alone,' said God. A human being totally alone is an anomaly for God and for us. Each life is a story we create ceaselessly with those living around us. We are born from a story woven by our parents which enriches their personal histories, which depend themselves on other histories. Close relatives surround us, where close means the one to whom I am not indifferent, the one who takes part not only in my wounds and sorrows but also in my successes and joys. The man who dies alone shocks us because he seems surrounded by indifferent people.

The fundamental relation we are made of is the one God weaves between him and us, sometimes without our knowing it. When in human history, an event appears that shakes it and modifies it over a long time, we can imagine that this shock will have repercussions on non-indifferent relatives.

Illness as crisis

There are times when our life goes as it should, without watching it. Our body works and accepts our demands. We meet its limits

but accept them as normal. We can play the social roles we have chosen and carry out our plans. I can act as a husband, as a father, as a practitioner. If I am retired, I can carry out the activities I had planned, taking into account the fact I am no longer twenty. Suddenly, in the course of this well-organised life, illness appears. The trouble develops insidiously until the diagnosis comes down like a blade, without leaving any hope that things might recover. Illness nearly always comes by surprise. Suddenly it calls our personal plans into question and raises questions about our ability to maintain our professional, social and family roles. Often the shock is immense and it will require major adjustments to family, social and professional life to start again a story which could be given new meaning by illness.

Two of the many effects chronic illness may have on our lives are the shaking of the identity of the sick person and the existential suffering which follows. Illness changes lives. Chronic illness is something that will remain permanent in the life story of the patient. It becomes part of this story and transforms it. We can see changes in aptitude, limitations of possibilities and accentuation of feelings of fragility. Often an increased dependence on other people appears, whether relatives or caregivers. Sometimes this dependence on other people can't be accepted without an extremely painful challenge to self-esteem.

Illness will cause the sick person to look at himself anew, stripped of false certitudes, self-confidence, and pretensions to independence. 'For you say, "I am rich, have become wealthy, and have need of nothing" – and do not know that you are wretched, miserable, poor, blind, and naked' (Revelation 3:17). As long as all is well we live easily in the illusion of autonomy and invincibility; illusion disappears in difficult times. This shaking of personal identity hurts and that is perhaps what makes us suffer most in a chronic illness. Suffering goes beyond the biological level and becomes existential. The illness, which started in the body, overflows into the whole of life; life itself becomes the place of suffering. As the suffering overflows unavoidably from biology to my whole being it reaches my real life, my network of close relatives. The crisis of illness is a crisis of the whole family.

Illness as family crisis

Illness in the life of a person emerges in their family group too. On the one hand the arrival of the unforeseen into everyday life shakes and modifies the family balance, on the other, the family's way of reacting to it will influence the evolution of that illness.

Illness prevents any individual or family plans outside the illness itself. Cancer or dementia is all that is seen. The prognosis of progressive deterioration seems to close the door to any future. We often feel that the sick person and his family are literally petrified, waiting for death to come. Illness prevents hope.

Becoming the centre of his family's interest, the sick person attracts all energies and attention. Most things are done to him out of a sense of faithful duty. 'We must back one another up' or 'We are a united family' reflect the wish to act as an ideal family in adverse circumstances. This may strengthen the family but not without perverse effects. Thoughts of abandoning the sick person or of being in good health oneself when the other person is suffering may lead to guilt. Adolescents may feel it is their duty to stay and sacrifice their grasp on independence in order to support the sick parent.

Illness weakens social inclusion

Chronic illness often isolates the family group by weakening its links to the wider community. Some families can't speak to people outside because they think that what they are living through is so special that only they can understand it. There is also the difficulty of presenting the sick person to society as if one had to justify oneself in front of what often causes horror, rejection, or just the fear of not knowing how to behave.

Illness makes families vulnerable, putting relationships under stress and playing with faithfulness, dependency, guilt and the wish to achieve the ideal. It makes the family suffer in the same way as the sick person suffers by seeing their identities shaken. A major source of family

suffering consists in anticipating unavoidable losses. The main difficulty families have to go through in the case of chronic illness is the climate of uncertainty, even more difficult than bereavement itself.

Family as a place of resolution of crisis

It is most important that the process of healing takes account of the whole family group. The way the family reacts influences the course of illness. There is great danger in medical care of focusing on what is immediately visible, the sick person and his biological affliction, neglecting the existential tempest it has started. Once illness overflows from the biological into the existential, the whole of the subject's life needs to be addressed. As his existence is unavoidably written in the collective, recovery cannot take place outside this dimension. Crisis resolution or even healing a chronic illness does not mean its disappearance; rather it allows for the possibility that the patient and his family go on living and weaving their human stories in new ways. The one that was wounded, who fell down, stands up again and starts walking, even with a limp (see Genesis 32).

Illness freezes history partly because, when healthy, we imagine the immediate future. 'When I grow up I will be an engine driver, when I pass my exams I'll get married, when the children have grown up, we will travel' and so on. This imagined future becomes suddenly impossible. Living with a chronic illness means filling again this space before us that emptied suddenly. For the family it means being able to imagine another life, a life which integrates the loss in a new story and even incorporates the death of the person. The wife of a patient with Alzheimer's disease said: 'We must go from the hope of healing to supporting presence.' This implies first the shock after receiving the diagnosis, the hope that it is only a bad dream which will soon disappear. Then something happened to enable acceptance of the unavoidable, a new start, close support and going on with the sick person, while leaving him enough space to go on being himself.

The family affected by chronic illness will have to make an effort to rebalance and reorganise family relations thereby re-establishing

family solidarities. Illness brings a loss of balance between strength and weakness making it necessary to reorganise dependencies. Perhaps this is the most difficult task of all: to trust the other when you used to give your opinion, to ask for help when you used to be the one who helped or to start leading when you always used to rely on others.

The family will draw on its own history and tell its stories of facing difficulties, illness and loss in the light of this new experience. The meaning of the family's history will be renewed as they exchange words so that each one can give and receive from the other, going beyond their normal boundaries of conversation.

Intervention of the care givers

We often see the family fall into panic, unable or unwilling to face the change required by the crisis of chronic illness. The family may hand the sick person over to care providers. The family can't face the change, hence others are asked to resolve the problem in order that things may continue as before: 'Cure him, free him from his sickness and give him back to us as he was before in order that we might continue to live as before' or 'Look after him, we know that nothing can be done but the burden is too heavy for us, take over, don't force us to adapt ourselves.' Facing this presence-absence, the family group cannot re-establish its equilibrium after a period of mourning, precisely because it is a pseudo-death. Communication is blocked and evolution impossible.

Another situation causing break up is the exhaustion of the family. They wanted to bear alone the weight of the illness; they didn't reactivate the social links broken at the beginning of the disease. It is normal in such a situation for the family to withdraw into itself. It is the family which suffers and is wounded, and the family alone can solve the problem. Forced by exhaustion, whether by choice or necessity, there is a time when the family must seek bonds with caregivers in the wider community.

When caregivers enter the story played out by the family and the illness their main role is to take into account the influence of the sickness on the family:

- They do not judge the family, whose attitudes are the result of a long history.
- They do not take the patient away from his family – recovery is still a collective phenomenon.
- They recognise the family situation, myths, roles, the illness itself, and relationships frozen in time.
- They find new ways of communicating when words are no longer possible. Acting from outside, the therapist helps the family dynamic make necessary changes. Thus he opens up the possibility of rebuilding or maintaining an effective network in which the caregiver has a place too.
- Speaking about the future (the likely course of the illness including death) the carer reduces tension, enabling the family to incorporate it into rebuilding their story.

Conclusion

Chronic illness is an event at the intersection of several stories (those of the illness, the individual, the family through generations and the history of the larger social group in which this family fits), written in time and changing, not ending, them. As caregivers we are not outside these stories.

I was surprised to see how much, as a son and member of the family, I never tried to put a name or a diagnosis to my father's illness. I had a different outlook from the medical one. I wondered how my mother could live through it. I worried about what was going to happen, how we would react and adapt ourselves to new situations. I became aware that, despite the diagnosis, I never considered my father as 'ill'. This discovery continues to prompt questions for me.

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