

Keynote speech by Baroness Pitkeathley October 1st 2008

A view of caregiver movement today and tomorrow

It is a great privilege to be here and I thank very sincerely those who have asked me. I am particularly privileged to join you in this vibrant and brave city and in this institution which is so significant and highly respected. It is wonderful to be reacquainted with those of you I have already met at Carergiver conferences throughout the world and to meet those for whom the carers issue is comparatively new. You must forgive me if I use the word 'carer' when you prefer 'caregiver' - I will try to remember but may slip up sometimes. But the terminology is not that important. What is important is that it is very evident and growing daily more so that what is being established is a global carergivers movement. No one knows that better than Gail Hunt, to whom I pay the warmest possible tribute for her indefatigable work to help embryo caregiver organisations all over the world. However different the situations of these organisations, however different the policy context in which we are all working, the issue which unite us - the mission to get carergivers recognised and supported is common. That means we can learn from each other, profit from each others successes and, just as importantly, learn from each others mistakes.

If the carers movement in the UK has had any success - and it has had a great deal - that success has principally been about what I always call- **Turning a private trouble into a public issue**, about raising public awareness of what was until comparatively recently a private matter so that legislators and policy makers simply cannot ignore it. That is something we are all trying to bring about it. So what I want to do this morning, from the privileged position of having been in this

business of caregiving for more than 20 years now, and as Vice President of Carers UK, and as President of Eurocarers is to give you my thoughts on the development of the movement world wide, at the factors which help that growth - with particular reference of course to our experience in the UK.

Since I don't do PowerPoint it might help you to know that I base my thoughts around 3 words beginning with P

Profile

Partnerships

People

Why has this movement gained in momentum and is gaining in success? One of the most important factors is its **increasing profile or if you like, its popularity**. I think this can be related to two things - to numbers and to the notion of being deserving.

Giving Care is ubiquitous - it will happen to almost everyone. Moreover caregiver organisations have always been strong on numbers - have made good use of them and have been in the fortunate position of the numbers constantly increasing in their favour. It is always a very sweet moment for me and all in the carers movement to hear Prime Ministers Tony Blair and Gordon Brown, the Princess Royal repeat the figure of carers saving my nation £110 billion usually coupled with an acknowledgement that they receive nothing like enough back in terms of benefits. So numbers and value have always been significant but there is a third element, which cements the other two, and that is the cause itself.

Carers are seen as deserving. Caring is part of the 'social contract' - over our life course we are all likely to give and receive care. Politicians will not of course talk about deserving or undeserving but the reality is that some causes are easier to argue for than others. The political language changes and we move from basic values to the importance of the family, to rights and responsibilities but much is coded and the notion of deserving is never far away. The good fortune of the carergivers movement is that although language and assumptions may change, they themselves have never been a group which could be sidelined or viewed as doing anything other than more than their fair share. Whatever the pitfalls of such a deserving cause one huge advantage is the fact that politicians and policy makers on all sides find it difficult to oppose and this has been of immense value in sustaining the movement. Caregiver movements worldwide are daily growing better at exploiting the fact that there are a great many caregivers and they are universally seen as deserving - facts which hugely help when you are trying to establish a profile for a cause - especially with the media.

The media in all its forms has always been of great significance in the caregiver cause. As long as 20 years ago in the UK we took the decision that no media opportunity should ever be missed. Moreover we would always find a carer who would be willing to be filmed or recorded so that it would be the image of the caring itself which lingered - not that of a talking head. This has to be extended too to accepting any speaking engagement which is offered and to any invitation to sit on this committee or take part in that consultation. No one knows better than I that such things are tremendously time consuming and resource hungry and can be a huge burden to small and under resourced organisations.

But opportunity is all in these situations and hard though it is we have to seize whatever opportunity is offered if we are to capitalise on the innate popularity of our cause.

Let us not forget either that the higher the profile of a carers organisation in government circles or in the media the more likely it is to attract funds from as wide a variety of sources as possible.

What carergivers organisations can also do and have done very successfully also is to research the caring situation - either themselves or by commissioning research from other agencies. Again this has been particularly significant here in US, Europe and Australia.

Let me turn now to my second P- and this is the word **Partnership**. These are of the essence when growing a carergivers movement and I cannot stress too strongly how important it is for organisations involved in the caring business to work together. We formed a Carers Alliance way back in the 80s in the UK and many other countries, notably NZ have found alliances very important when developing policy.

We always knew that singing from the same song sheet was absolutely vital and this was especially the case when we moved in to trying to bring about changes in legislation.

The carers alliance, in finding common cause across a huge range of organisations representing disability and disease specific causes really paid off at that point. If a Minister or an Official had been able to find

disagreement among us, or any sign of a lack of commitment, they would have had an excuse for not proceeding. Disunity was simply not an option. **This is a lesson I want to highlight.** I am sure that politicians the world over are the same. If they can find what they think is a valid excuse for not making changes, they will use it. There is nothing more vital than a unified approach. Any divisions will be exploited by politicians and prospective funders will be disillusioned so if you **must** disagree, do so in private. No one, least of all the carers to whom we are committed will benefit from disunity. This may mean compromises on all sides - but negotiation and compromise is all in these situations. For we should never forget that caregiving does not take place in a vacuum and that other movements have been developing alongside it. The disability movement is an obvious case in point as is the older peoples movement. As caring became a new term to describe an old situation, so the words used to describe disability and the attitudes surrounding it have changed too. It is no secret that in my country and in others there are those at the very radical end of the disability movement who have resisted the growth of recognition for caregiving, fearing that it may undermine the move towards independence of people with disabilities, stereotyping them as a burden and fearing that the provision of services may become overly biased towards carers and thereby work against the interests of the disabled person.

In addition many countries are now looking at aspects of age discrimination, to afford older people the same level of protection that we aim for in terms of race, gender, sexual orientation and so on. Promoting age equality may conflict with trying to get the rights of those who care for older people higher up the agenda. Such ideological conflicts are not unknown in any campaigning sector and it would be unrealistic to

assume that carers would be immune from it. But what carergivers' movements throughout the world have done or are managing to do is to work in partnership with the disability and older peoples movements, arguing that carergivers are on the side of disabled/elderly people and that better recognition and better services would benefit both parties. Now no one can pretend that such partnerships are easy. We have to deal with competing aims, egos — oh the egos you always find when you try to form an alliance. And we have to deal too with different priorities. Most of us who have promoted and worked with alliances have had a moment - many a moment - where we have thought 'is it worth it?' Why not go it alone - wouldn't it be a lot easier? Well! Yes, probably but not nearly so effective as most of us have found out. A well-organised partnership or alliance does not mean duplication as the focus is different and specialised, neither does it impede individual organisations pursuing their own priorities - the river that is the carergiver movement has many tributaries after all. But what we must all realise is that the power of a united voice when pressing for changes in policy can never be overestimated, strength in numbers really does work.

If time permitted I would now add an extra P here and talk about politics. As a campaigner/lobbyist who by the strange workings of the British political system has become a lawmaker and a Deputy Speaker in a Parliamentary Chamber, it is naturally a subject very dear to my heart. Moreover the success of the Carer movement In UK in getting 3 separate Acts of Parliament and 2 Carer Strategies passed into law, is worth boasting about I think. BUT As well as the shortage of time I have learned that talking about political processes internationally is a tricky issue so I will just briefly

summarise what I think should always be remembered about lobbying on behalf of caregivers. Because that is what we are all doing in our different ways and how fortunate we are to be doing it here in such a powerful forum whose support could make a difference to caregiving everywhere.

The policy developments we ask for should be sustainable and credible. They should also be well researched including seeking out the real financial cost and grounded in the reality of the actual political situation in which you are operating. We must be aware of what realistically can be achieved. Often we cannot hope for a great reform of the legislation, but must work on getting minor amendments which will benefit carers. Sometimes it is very hard to convince stressed out caregivers that this is the best approach but it is possible as you prove to them that this measured approach is most times, though not all, more likely to bring about the desired changes in the end.

The grounded approach to campaigning is necessary as is ensuring that what you seek is

- in the interests of carers and former carers
- achievable
- has pragmatic solutions

This is where learning from other peoples experience can be so useful to emerging caregiver organisations.

The lessons which have been learned and must be learned by us all if we are to engage in successful lobbying on policy include:

- Political sophistication - in order to be politically neutral you have to be politically sophisticated
- Knowing which battles to fight and which to leave alone
- That you never get there - there is always more to do

In spite of the huge legislative progress made for caregiversUK for certain, their problems are a long way from being solved. Most carers still in the UK are like carers all over the world - unrecognised, uninformed, unsupported. But carers do have legal rights now and that gives them infinitely more negotiating power than before, infinitely more public profile and infinitely more recognition in public policy terms and on the political agenda.

For example

- they have a right to assessment of their own needs
- to services to meet that need
- to ask for flexible working patterns
- to a normal life — to pursue education, leisure and time off

It is unthinkable now that any political party seeking office or any local or health authority providing services would not include carers as a priority group. Caregivers are well out of the closet and there is no putting them back and I am glad to say that increasingly that will be the case throughout the world.

But it will never be easy which is a tremendous challenge for caregivers and all those who work with them. But twas ever thus with all causes which are worth fighting for. This relentless process of selling the

message is the real and continuing work of the carer movement throughout the world stage. Because make no mistake, we are going to need all the strength we can muster together if we are to be able to face the challenges which await us as this century progresses. We have to consider issues such as 'what is a normal family unit?' as divorce, remarriage and population mobility takes its toll. What is my moral obligation to my ex mother in law? Have my step grand children any moral commitment to me or for that matter to my daughter their stepmother? What does each society expect of its caregivers and potential caregivers in the present mosaic of family relationships? In most developed countries demographic predictions about the numbers of disabled and older people in those societies make it imperative that caregivers are put at the centre of the governments agendas. The data are not ambiguous about the need. CarersUK predicts that in 20 years time 3 million more carers will be needed to provide the same level of care which we see today.

Population mobility is another challenge, The inward flow of migrants, both economic and asylum seekers is bound to affect patterns of caring, whether caring at a distance as families become more spread out or caring across different cultural boundaries and expectations. How do caring patterns and expectations of family work out in these different and very diverse communities?

I see no prospect yet of the future agenda being easier or complete. Nor can we be sure how the current crisis in the financial underpinnings of many countries will affect this agenda in the future – in terms of family finances and overall prosperity.

I am aware that I am fortunate to live in a country where access to health care, free at the point of use is not seen as a privilege or a concession but as the entitlement of every citizen. Yet even in the UK we are engaged in extensive discussions about just how much the state can now afford.

My last P is People.

There can be no final account written of the carer movement
However deserving the cause, however good the information, it takes people to take it forward.

It takes the carers themselves who are willing to find that extra bit of energy, that extra bit of hard won time out of their already overburdened lives, to start a group, to put together that information pack, to share ideas and tea and sympathy with others. It takes carers who are willing to talk to the media, to have journalists and film crews come into their homes and film them for hours for what translates to two minutes on the screen.

It also takes leaders, People who are willing to put their heads above the parapet and take a principal role. This is not always easy. Trying to balance competing agendas, to satisfy many different needs while providing information and lobbying politicians and raising funds is not simple. It may often bring satisfaction and a sense of achievement but undoubtedly it brings brickbats too. Most leaders of the movement have at sometime been accused of working to their own agenda rather than to that of carers themselves.

And of course it takes politicians and policy makers who are willing to listen, to innovate, to argue for caregiving in the face of discouragement and resistance.

Having groups of such people has been the great good fortune of the caregiver movement so far, in my country and as we are increasingly seeing, throughout the world. It is that commitments and persistence which has brought us here today.

Working together has brought us the recognition we have achieved so far; it will sustain us I am sure in all the many challenges that await us in the future.