

[Speech by Baroness Pitkeathley,](#)
[Eurocarers AGM – Berlin, 26 May 2023](#)

Thank you for the introduction. I have had the privilege of being the 1st president of Eurocarers and have followed your progress with interest and admiration over the years.

As you embark on a new strategy it is an honour to be asked to share my thoughts at the end of this important conference. Inevitably, much of my thinking is formed by my UK experience, first as CEO of Carers UK and later as a Parliamentarian. I must own at the outset my great regret that the UK is no longer in the EU - but I am a European in my heart and in my head so I am especially honoured to have a role here. I have also had the privilege of launching carers' organisations in many different countries all over the world – Australia, New Zealand, Canada and in many different European countries. I have been involved for 40+ years, since before many of you were born, so though I know I have been called the mother of the carers' movement perhaps grandmother or even great grandmother would be more appropriate.

So, I want to speak today as a grandmothers do. I want to acknowledge your successes and offer some advice/warnings if you will excuse me being so presumptuous. I would like to give some thoughts on the plans you have going forward on the three separate issues of **Carers Voice, Evidence on carers and Carer Policy.**

As far as voice is concerned, congratulations on the huge progress made and the difference which you have all made to the lives of the caregivers of Europe - and beyond - indeed the world.

What has been so inspiring about joining you here after the history we share is not only the range and extent of membership - 76 carers organisations and 26 countries but the opportunities which exist in the future for further work as your strategy is developing. I am saying 'you' here in my grandmother role but mostly my instinct is to say 'we' because I feel as much a part of the carers movement now as I did in 1988 when Carers UK hosted the first international conference in London and delighted that it is now a much bigger movement of which to be part.

We have turned what was once only a private trouble into a public issue. How have we done that? By a combination - a clever combination I would say - of using evidence and experience. The research that has been produced is awesome in its range and in its depth. In the early days we set great store by getting numbers and that is as important as ever. No one believed there were as many carers as there have turned out to be in the UK until we managed to get a question included in the Census and the General Household Survey but when we got the numbers, they stunned everyone and enabled us then to move on to assess the value of care

as Eurocarers has done so successfully — over 350 billion Euros every year is a very powerful figure. The size of our constituency has always been its strength - as has its range.

At first, policy was always about older people and their carers - now we understand that the caring issue takes in all ages both as givers and receivers. Nowhere has this been more obvious than in the identification of young carers - initially overlooked because systems were reluctant to admit their existence, let alone the needs they had and the huge long-term effects that caring as a child or teenager has on your later life.

But we have not forgotten that the carers voice is the most powerful tool we have so we have all learned that we must allow the carers to speak for themselves in media interviews, articles or at conferences. However good the academic research is, what policy makers and the public will remember is what the carer said about how they felt when they were alone, unsupported and no one was listening.

By these means we have established that carers are a highly important stakeholder group in all social policy areas and Eurocarers has established itself as a respected and reliable source of policy information and influence. We must always be aware that getting the voice of carers heard is dependent on the strength of the organisations which represent and include them, so we must ensure that those organisations have a strong base and are enabled to command respect. Establishing a new area of influence is not easy and the carers movement had a particular disadvantage - that it was hidden in plain sight - caring is so much part of human relationships that we fail to recognise it as a separate issue - with its own agenda . All emerging carers' organisations report that they have opposition initially from other areas of interest — of course from governments and service providers who are reluctant to identify another area of need, but also from disability organisations which can see carer agencies as a threat. Part of the success of the carers' movement has been its willingness, its commitment, to working in partnerships with other organisations. Partnerships which have been so much in evidence here in Berlin and I do want to acknowledge how successful Eurocarers has been in promoting partnerships and in understanding how important they are.

In the early days, it would have been easy to come into conflict with, for example the disability organisations which were also fighting for rights for their own constituency - and I know this has been a common experience across the world. But the carers movement has always made common cause with these and other organisations who have an interest in either a specialist condition or a specialist need. This was driven by two reasons; first, carers themselves have never wanted their needs considered in opposition to those of the person they cared for, while acknowledging that they may not be the same. Second, we have always been aware that too many movements have split because of competition for ownership of an issue. All the energy then goes into in - fighting and there is less for fighting the cause. We all know that politicians may like this because it lets them off the hook. It is always useful for politicians to be able to

say to an organisation which is lobbying them – ‘Ah but this other organisation says something different’. So maintaining consensus has always been vital. Caring is after all everybody’s issue and the maxim has been that if we do not hang together, we shall surely hang separately. Organising and making common cause with relevant organisations has been and will continue to be an important part of our progress.

And it is not only partnerships between carer organisations which are important but those other connections which can make our lives easier or more difficult. We have also been grateful for and seen the importance of the support of statutory and governmental organisations such as social services departments, health departments, welfare agencies and so on in the partnerships which have been so influential in the stages of recognition for carers. Partnerships are important when the carers movement is being developed and remain so, not least in those connections with academic institutions whose research has been so significant and which continue to identify new areas of interest and possibilities for development. It is important too to recognise the support of commercial companies in our movement (Evidence in sponsorship here today). Commercial companies have helped Carers UK to develop and promote its messages and some CEOs of huge organisations have been surprised to find that, not only do they have large numbers of carers in their workforce, but that they themselves are in fact carers in their private lives. Government’s departments, commercial companies and academic institutions are all an important part of the constituency that is carers and Eurocarers and its members have cast the net wide to gain recognition and support. All the things I have mentioned are huge achievements and we should allow ourselves some celebration and congratulation.

BUT and this is where I come to my warnings - we are constantly aware of how much remains to be done - how most carers are still unrecognised, unsupported. When you read and hear the stories which carers tell, in person or via the media, what is striking is not how different they are from the ones told 40 years ago but how similar they are.

Yes, carers have rights we would not have aspired to then, but so often there is no money to provide the services to which they are entitled and many local authorities, now so short of money, are putting more pressure on carers, not less.

The rights to financial support, not concessions but rights, which have been so hard won by predecessors are under threat as our governments pursue policies of austerity, cuts and means testing, because of financial crises and national debts as a result of pandemics and wars and financial insecurity.

Carers share their worries now not only in carers groups as they used to but also by web chats and Twitter and WhatsApp but the worries that they share are the same. Indeed the worries which carers share across the world are striking in their similarity.

In the UK, 2 million new carers each year take up the responsibilities of caring and too many feel as ill-informed, unsupported and unrecognised as they were 40 years ago. Their own health, physical and emotional just as much under threat, their own financial security present and future, just as much undermined. And the problems which carers share with each other and with their organisations will be as familiar to all of you as they are to me.

Too many voices are still silent or unheard.

I often used to say that the aim of carers organisations should be to work themselves out of a job - because all carers would be recognised and supported. I do not think there is any danger of us doing that in the foreseeable future! Much work awaits us.

Let me turn now to topic of evidence.

I have already mentioned our debt to academic institutions and the research which has been accumulated across Europe and by Eurocarers is astonishing in its breadth and in its range.

The interest of notable academic institutions and highly qualified researchers is very gratifying as are the innovative approaches used. Carers have proved to be a fertile field for higher degrees and educational attainment and there is a lot of it! Evidence based advocacy is a guiding principle and must remain so.

BUT many issues and areas remain to be explored and some are so underdeveloped that it is hard to predict how they may turn out. But let me offer a few thoughts:

The lack of awareness of carers issues remains a major concern across the EU as a whole and across many member states. We lack comparable data about needs and about how those needs are or are not met. There is a lack of awareness about the economic effects of caring or about the contribution that carers make to the individual economies of member states. We still need over-arching strategies as well as comparable strategies across individual countries and of course we are all at different stages of development in all these areas.

We are still in need of a common and totally understood terminology. We are a good deal more advanced than when I began in this business when the word 'carer' was not in any English dictionary and was frequently misspelled as 'career'. We used to have teachers ring us up and ask if we could give career advice to their year 10 students! We use and understand carer/caregiver/care provider and it gets us by but the term 'unpaid carer' is in itself flawed because many do not find that this label reflects the nature of the care and support they provide or the fact that caring is dynamic - based on the history of a previous relationship. Many people therefore choose to use a word which better describes that relationship, such as mother, husband/daughter. I sometimes wonder if in the UK we have been TOO successful

in getting the word into common use since everyone now wants to be described thus - nurses, physios, therapists, care workers, parents. When during the pandemic people in the UK were out on their doorsteps on Thursday night clapping for carers - it was not the unpaid carers they were acknowledging but rather the services of doctors and nurses in the overstretched NHS.

So we need more evidence on all these things but I wonder too if there are some more challenging questions to which we should be seeking answers?

For example, we want carers to be a special case and yet is what we want is for them NOT to be a special case - don't we want for carers what every human being wants?

To live in a place we call home, with the people and things we love, in communities where we look out for each other, doing what matters to us - to live, in the language of a recent House of Lords report - a gloriously ordinary life. And yet in order to gain recognition we have to be constantly making the case that carers are different and special. We have to get the world to accept that caregivers are an overlooked category of people who are experiencing social stigmatisation and exclusion. Since most of us - probably all of us - will either be carers or be cared for in the course of our lives why is it not more obviously recognised that this is a matter of human rights? Can we get caring accepted as a protected characteristic when it comes to human rights? BUT if we did achieve this, would it put more pressure on our fragile support systems and thus be counterproductive?

Another question for researchers is: Should we be pressing for preparation for caring ?

We are all only a hairsbreadth - a fall, a sudden accident, a diagnosis, away from caring responsibilities. For some, caring is an interruption in a relatively steady pattern of life for some, it is a constant, but that can change for any of us at any minute and we should all be more prepared than we are. How many families actually sit down and discuss how caring will take place when the need arises? And should that include giving all carers the right to choose NOT to be a carer, the right to choose the role or not as you say in your literature? Do we acknowledge that the changing patterns of family life may change caring obligations substantially. What was my moral obligation to my ex-mother-in-law? What is my daughter's obligation to her step father? We need more understanding of these things and certainly we need to discuss them more openly. One of the advantages perhaps of the pandemic was that it brought the need for care more sharply into focus due to the pressure on care systems and the breakdown of established support systems. We should build on that learning, remembering that when there are pressures on national budgets it is always tempting to ignore the needs of carers, not least because service providers almost always mistake the amount that carers are going to demand - always thinking they will demand more when this may not be the case. Co production of services might overcome these misunderstandings but do we know enough about and how that might work for carers?

Are carers care providers or are they care receivers? As Norman, one carer said at a recent meeting of Carers in Westminster - 'am I part of the care team as an unpaid carer or am I a problem to be overcome?' Professional attitudes to carers vary hugely and vice versa and we need to know more about how these attitudes affect both the delivery of services and recognition of the carer's role.

So I have given some ideas for more research but have not even begun- and nor do I have time to reflect of how the development of technology, let alone AI will affect our work. And these gain currency how will different forms of care meet the needs of carers? [I know interesting discussions and workshops have taken place here.]

We must be prepared too to look at how the special needs of minority ethnic communities and the LGBTQI community — some of this work is ongoing and we must build on it.

We also have to ensure that evidence of carer needs is not confined to health and social care or welfare services. Caregivers need recognition from transport services, from housing services, from designers of equipment and clothing, from food producers — the list is endless. And of course from employers and trade unions. Most carers live in poverty, since caring itself costs money and many give up paid unemployment. For this not to be recognised and accommodated is the worst short-sightedness.

Legislative changes to improve carers job security and flexibility are urgent in most countries, especially those like the UK where shortages in the work force are very concerning - why ignore the huge numbers of carers who want to combine paid work with caring and when their caring comes to an end ,why not value the skills they have learned in their caring role and recruit them into the work force ?

So there is a series of challenging questions needing to be addressed as we go forward and I know that the close relationships across Eurocarers and across Europe will facilitate this.

Let me turn finally to policy because changing and developing policy is very heart of what we all want to do.

We have heard examples here about the Successes there have been in influencing policy in many countries and we have many reasons to celebrate. There is though I think a dilemma for many of us as we campaign for policy change. I call it the fight between passion and pragmatism.

The way we have go about influencing policy and bringing about change - is at odds with and may be in direct conflict with- the passion many of us feel about the carers issue. I feel this strongly at a personal level. I felt it when I was a full-time campaigner for carers and feel it

even more now, I am a full-time politician. What motivates me- what motivates so many of us, is the passionate commitment I have to making life better for carers.

BUT in order to do that, I have to work within a political system, one which is filled with bureaucracy and procedures which have to be followed, norms which have to be obeyed, differing political views which have to be accommodated and they do have to be accommodated if our movement, if our organisations, are to be respected.

Because how do we gain respect? My experience is that it is gained through wise campaigning and achieving some successes; getting some wins.

Wise campaigning means remembering that health policy and social policy changes rarely come about by revolution but in small slices- salami- like as I always say. The changes which have happened for carers over 40 years taken together are enormous, but each was achieved through relentless commitment to the cause, by endlessly promoting it, by constantly forging and re forging relationships with politicians and civil servants and bureaucrats. Ministers change and must always be thanked, no matter how small a concession has been made. Officials and bureaucrats move on. Just when you think you have one really engaged, they are promoted or demoted and you have to Start all over again. You can never afford to miss an opportunity and never be disheartened by apparent failure or the slowness of the pace. The carers' movement has always been reasonable in its demands, indeed has prided itself on the reasonableness of its arguments and has always understood that firmness of purpose is no excuse of being unadaptable. When you negotiate with government structures at any level, local, regional, national or international, you have to be flexible, always able to see when a change of position might help you gain a little territory. Moreover it is easier to be successful and to be able to promote that success, if your sights are not set too high. But this does not come easily because our sights ARE set high - we want a better world for all carers.

In UK we have just seen a new piece of legislation on to the Statute book- will receive Royal assent any day now. We have been working for it for about 15 years- It gives carers the right to 5 days unpaid leave a year. FIVE DAYS UNPAID LEAVE A YEAR I HEAR YOU say after 15 years? How derisory is that? Not much of course and I am pleased to say that many employers in UK are far more generous than that, thanks to much work by Carers UK over many years. BUT the right is what is important- not to be dependent on the good will of your employer nor your own ability to negotiate. The right. [Next thing will be to research how this piece of legislation is working and to use it to get 5 days paid leave , to see if we can get each party to promise more in their Election manifestos and then and then...]

Many of you will know that Carers UK has been successful in bringing about changes in legislation through our Parliament which have benefitted carers. We have always taken the view then that it was better to get something on the Statute Book from which we could build

than to hold out for greater rights which were not yet going to happen. So constantly subduing what you desperately want to do is part of the DNA of any campaigning organisation and of course it never ends. You have to make sure that whenever there are policy changes you are on the case and always be monitoring every announcement to assess if it has implications for carers. You manage to get a National Carers Strategy into law in your own country, or even across the EU and then what- ? well of course you will have to ensure it is regularly updated, that it remains relevant to new situations, new challenges and all the time you are impatient, wanting to go faster and you cannot. But it is important to remember that 'salami like' illustration. You may not get the huge win you were seeking but a lot of small wins can add up to a big one and one small win, one small bit of progress can add up to a huge change in the life of an individual carer. As one said to me, I felt I was the only person in the world in my position. I was isolated, alone, unrecognised even by my nearest and dearest. When I found the Carers organisation and that someone understood and not only that, they were fighting my corner, it made every difference in the world to me. Experience of hearing someone say that will be repeated everywhere in this room today. And that is why we cope with the frustrations of influencing policy, why we accept the slowness of progress, why we accept failure and live to fight another day = it is for the difference it will make to that individual carer.

In conclusion I return to being a proud grandmother in congratulating you all on how much has been achieved and on the prospects for the future. I am a natural optimist, - all campaigners need to be and I look back at the years of the development of the carers' movement with great satisfaction. However much remains to be done we must never forget how much we have achieved together. By whatever measure you use- voice, evidence, policy our movement has had huge success and I know will achieve more in the not-too-distant future.

And when I hear the word 'success' I think always of the quotation by Ralph Waldo Emerson; To leave the world a little better, by a healthy child, a garden patch or a redeemed social condition- to know that even one life has breathed easier because you have lived- this IS to have succeeded.

Each one of us has the opportunity in our work for carers to ensure that even one carer breathes easier but going forward together in partnership we can bring about a redeemed social condition for all the carers of Europe. I know we shall do just that.