



























**COMHCHOISTE UM GHNÓTHAÍ
SÓISIALACHA AGUS
TEAGHLAIGH**

**JOINT COMMITTEE ON SOCIAL
AND FAMILY AFFAIRS**



The Joint Committee met at 11 a.m.

MEMBERS PRESENT:

Deputy Cyprian Brady,  	Senator Martin Brady,  
Deputy Catherine Byrne,  	Senator Larry Butler,  
Deputy Thomas Byrne,  	Senator Nicky McFadden,  
Deputy Joe Carey,  	
Deputy Seymour Crawford,  	
Deputy Olwyn Enright,  	
Deputy Mattie McGrath,  	
Deputy Michael McGrath,  	
Deputy Charlie O'Connor,  	
Deputy Róisín Shortall,  	

DEPUTY JACKIE HEALY-RAE IN THE CHAIR.  

► **National Carers' Strategy: Discussion with Carers Association.**

Chairman:   The joint committee will hear a presentation by the Carers Association on the national carers' strategy and the role it will play in supporting family carers between now and 2016. I welcome from the association Mr. Enda Egan, chief executive officer, Mr. Frank Goodwin, chairperson, Ms Clare Duffy, social policy officer, Mr. Peter Cox, centre manager, Ms Mary McDonnell, carer, Mr. Pat Grogan, centre manager and Mr. Seán Dillon, head of services. I ask Mr. Egan to begin his presentation on the national carers' strategy and the role it will play in supporting family carers between now and 2016.

Before he does so, I draw witnesses' attention to the fact that while members of the joint committee have absolute privilege, this same privilege does not apply to witnesses appearing before the joint committee. Members are reminded of the long-standing parliamentary practice to the effect that members should not comment on, criticise or make charges against a person outside the Houses, or an official by name or in such a way as to make him or her identifiable.

Mr. Enda Egan: First, I extend our thanks to the Oireachtas Joint Committee on Social and Family Affairs and to the Chairman for affording the Carers Association this opportunity to appear before it this morning to give this presentation.

The context of the presentation is the current national carers' strategy, which has been committed

to by the Government in both the programme for Government and the national agreement, Towards 2016. The presentation's context also is slightly heightened by recent commentary in the press with regard to carers, carer's allowance and the half-rate carer's allowance in particular and how the latter might be under review in respect of current cutbacks and so forth.

Our presentation this morning will run for approximately 10 minutes. The approach will be first to provide members with a brief overview of who is the Carers Association. It will then consider how carers in Ireland are configured at present, as well as the role of family carers. Thereafter, we will get into the meat of the presentation, which will mainly concern the findings of two items of research that have been carried out recently. This will put on the table clearly the views of family carers regarding current services and existing supports for carers. We then will consider what needs to be done within the context of the national carers' strategy.

The Carers Association is a national voluntary organisation that was established in 1987. Since the establishment of the Carers Association, the issue of family carers has begun to receive a much higher profile. Until five to seven years ago, not much was known about family carers, who were a hidden group, which, to an extent, they remain to this day. However, the issue of carers has been put on the national agenda by the Carers Association and by a number of other organisations. At present, as an organisation we have 16 carers resource centres, approximately 37 full-time staff and approximately 278 part-time staff who mainly go into the homes of family carers to provide respite to carers. Our funding comes through the Department of Health and Children and the HSE. In addition, a certain amount comes from the Department of Social and Family Affairs and FÁS in particular.

As I noted, the role of the organisation mainly is as a lobbyist and advocate for family carers. We do a lot of promotion and awareness work, which run hand in hand together. We provide respite services to carers, which amounted to approximately 170,000 hours of respite in 2008. A huge part of our work comprises providing information to carers regarding what is available to them in respect of their rights and entitlements under various Departments, their entitlements within the HSE and so forth. A huge issue that has come under the spotlight in recent years is training for carers. We provide training to approximately 700 family carers per year. We also wish to welcome a recent announcement of dormant accounts funding, of which the Carers Association was the beneficiary to the tune of €572,000. It is to provide training to 1,600 trainers over the next two and a half years. A total fund of approximately €1.5 million was disbursed by the Government just before Christmas and this funding is very welcome.

While I imagine politicians are more familiar with this issue through their constituency work than anyone else, family care does not always necessarily involve a family member, as it also may be a good neighbour. It refers to someone who is providing full-time care and attention in their own homes to a person who more than likely is another family member although it may be a friend. In most cases, however, it generally involves mothers, fathers, spouses, siblings or children. At present, there are 161,000 family carers in Ireland, of whom slightly more than 40,000 do so on a full-time basis. That means the aforementioned 40,000 people are in their own homes seven days a week, 24 hours a day. They cannot leave their houses unless someone else comes in to allow them to leave to do whatever they must do. In other words, the person who is

being cared for requires full-time care and attention and there are more than 40,000 such people.

As for the carer's allowance, recent statistics show that approximately 43,500 people are in receipt of a carer's allowance. This figure includes almost 16,000 people who are in receipt of the half-rate carer's allowance. In other words, a total of 43,500 people are in receipt of a carer's allowance payment. At present, an examination of our nation's demographics reveal there will be a huge increase in the number of older people, which will increase by 80% between now and 2025. There also will be huge increases in the number of people with disabilities, as well as a vast increase in the number of people with dementia. It is expected there will be approximately 40,000 people with dementia in Ireland by 2020 or thereabouts.

Almost 5% of the total population are involved in family care. This is much smaller percentage than one will find in Northern Ireland or the United Kingdom and the reasons this may be the case can be discussed later. As noted earlier, the main part of this morning's presentation is based on the findings of two items of research that have been carried out quite recently. The first was carried out as a joint project between the Carers Association and the Irish College of Psychiatrists. It specifically examined the health of family carers and how their health is affected by their caring roles and has thrown up some interesting statistics.

The main statistic is that approximately 28% of family carers described their health as not being very good. Almost half have experienced being mentally or physically drained as a result of their caring role. Some of the key findings show that almost half of family carers surveyed had been diagnosed with a mental health problem. One in four carers have been diagnosed with anxiety problems and almost one in five carers have been diagnosed with depression. This tends to show that the mental health and well-being of carers probably is affected by their caring role to a greater extent than the physical aspect of their health. Physical aspects tend to include back ache, the main issue for carers, stomach ulcers and so forth. The findings clearly show significant problems around anxiety and, in particular, depression. Carers were not self-diagnosing. Rather, they had been diagnosed by doctors. These are strong facts.

I will briefly address a report entitled, *Listening to Carers*. We consulted two other caring organisations, namely, *Caring for Carers Ireland* and *Care Alliance Ireland*. The report, which was funded by the Equality Authority, was conducted at the end of 2007 and published by the Minister for Social and Family Affairs in May 2008. Its basis was the approximately 430 family carers who attended eight consultation meetings around the country and who told us how they felt about the HSE and Department of Social and Family Affairs services then on offer to them. In the coming pages, I will describe those carers' opinions.

The first heading is that of community and home care services. By and large, family carers felt that they were being left to their role where the service provider believed that a family carer was in place. This is in evidence across the country. If service providers are of the view that a family carer is in place, the services received by the family will probably be much less than the services provided to a family where no family member is present to support them. People were of the opinion that the providers' approach was at arms length, namely, that there was a lack of engagement if they felt that family carers were in place.

Long delays cause considerable problems and people felt that it could be difficult to access services if a family member was providing most of the care. In those situations, the delay tended to elongate. People felt that there might have been a lack of respect for and understanding of the carer by service providers in particular. They also felt that the HSE and the Government did not acknowledge the significant service being provided to the State by the carer. When the carer was in place, the services provided were not as good as when a carer was not in place. While there is evidence of inconsistency in service delivery, greater delays, increased difficulty in accessing services and the providers' arms length approach constituted the one consistent point.

On specific services and supports for the family carer, information was a considerable issue. People found accessing information when necessary difficult. This can cause stress and anxiety, as evident in the research by the Royal College of Psychiatrists. People also found that service providers lacked information and training. For example, someone telephoning his or her local HSE office might be sent from Billy to Jack because it is not Billy's area, but Jack then sends him or her on to Mr. Y. We received significant feedback in this regard to the effect that it was adding to the stress and strain of the role. Obviously, there should be a one-stop-shop where a person could get everything sorted out with a single telephone call instead of being sent around the houses.

The physical and emotional strain of caring was deemed detrimental to the health and well-being of the carer. Carers tend to neglect their own health because their focus is on the people for whom they are caring. Their health suffers as a result.

Needs assessment is a significant issue. According to consistent feedback from carers, there is no way to assess their needs and the State should put its shoulder to the wheel in that regard. Therefore, the person's needs would be assessed up front, thereby removing much of the unnecessary aggravation that might be caused when accessing services.

The main service that carers want is respite care, particularly targeted into homes, as this would allow them to rest or to leave their homes if, for example, they needed to do the shopping. The full-time family carer is in the home seven days per week, 24 hours per day. He or she is not in a position to leave unless services are being provided.

Concerning income support, the Government made it clear to us and the rest of the sector at the outset of the national carers' strategy that it would not abolish the means test for the carer's allowance or introduce a wage for family carers *per se*. I will run through this section quickly. From the point of view of the Carers Association, adequate income is a considerable priority. As we have been told that this issue will not be addressed in the strategy, there is no point in flogging a dead horse. However, it remains a key priority for our organisation and, given the research, family carers.

It is fair to point out that family carers acknowledged the developments and improvements in income terms in the past three to five years. However, there is still a long way to go and it is worth noting that the income level is starting from a low base. The difficulty with the carer's allowance is that it is means tested and does not take into account, for example, the fact that people give up well-paid jobs to provide care at home or the value of the work being done in the

home. Unfortunately, it takes into account the income of a spouse or partner. This is a major problem for people who have given up well-paid jobs and found themselves working much harder at home and under more stress and strain than they were while in paid employment, yet a partner's income is still taken into account. The rate of the carer's allowance is not in line with rates for similar work. The lowest point on the home help scale is approximately €13 per hour, but the carer's allowance is only €220 or so per week. There are considerable anomalies.

Another anomaly revolves around the fact that people are not entitled to a pension while providing care. Their PRSI contributions are not counted. We hope that the new carers' strategy will be able to solve this problem. The number of contributions required under the scheme to be introduced in 2012 may disenfranchise many family carers from their entitlements to pensions, a matter that must be examined, even in the current economic climate.

The other aspects that must be examined are employment and work-life balance. Of the 160,000 family carers, just over 40,000 are full-time carers. Some 120,000 people are involved in paid employment but at the same time providing care. They may very well be providing more than 40 hours of care per week. There are major issues in regard to the services provision and services in place to allow the person to engage in full-time employment but at the same time provide care at home.

In the past six years we have noticed an increase in people sandwiched into a position where they need two incomes in the family in order to put bread on the table, without having a lavish lifestyle. When a family caring situation arises, they are not in a position to try to give up the job because they need the income. They are trying to juggle care and work at the same time and this is creating major problems for people. Much must be done in the work-life balance aspect of this issue. More can be done within legislation to allow people to have more flexible working arrangements, to allow them to take time off to provide care. The carer's benefit, under the Carers Act, is helping the situation but more could be done if we introduce flexibility. Where carers are in a full-time caring situation, they see that their position will change in the future. They wonder what can be done and what is in place to allow the person to return to work in a seamless manner.

Social inclusion was a major issue for people. They felt that when the caring role is taken on, one's social life disappears. They are housebound and feel as if they are prisoners in their own homes in many cases. While the caring role is very rewarding, many issues arise, particularly in respect of isolation and transport, particularly if one lives in an isolated part of the country. This was a major issue for people who were not in good circumstances in terms of their social life. Their friends and social life were gone and this was making the situation worse.

The conclusion is that there must be a fair shouldering of the caring responsibilities by the State. The State needs to put its shoulder to the wheel. One of the major issues is that the State tends to step in when all else fails, when the family carer breaks down this situation needs to change. There must be adequate income support. The current system is not adequate, it is obsolete and we need a new system for remunerating carers. The other issue is the range of services for family carers. These must be targeted and the only way to do so is through a needs assessment system.

The organisation has picked four priority issues for today's presentation. I refer to the national carers' strategy. We have been told by the Department that the carers' strategy will not be as good as it could be if we were not in the current economic climate. The organisation does not want this situation to be used to lessen the effect. The effectiveness of the carers' strategy will be seriously affected by the economic situation in which we find ourselves. As an organisation and a nation there is a degree of understanding as to how that is the case. There is also clear understanding of the specific things that can be done to make people's lives much easier, to support them and to acknowledge that carers are providing us with 3 million hours of work per week in the health services. If that was taken away, where would we be?

One of the major issues is that this fact is not acknowledged. Representatives of the health services do not go to someone and say that there would be great problems without the person and that the health services will support the person to continue the job. According to this report, the health services withdraw and decide that there is already someone doing the work and that they will not examine it unless they come under pressure to do something. This is one of the key problems that this research has identified.

The carers' strategy must do two things. It must acknowledge that the economic situation is a problem in terms of the scope of the strategy. The strategy must set up clear review mechanisms and must identify the elements that will not be included because of the economic problems. The Government must be clear and say what it would like to do with those issues if it had the money. It must then say that, as it does not have the money, it will ensure the document is reviewed. The review should not be a case of examining what is in the document but bringing these issues back to the table and keeping them under review. If we are fair and honest in ensuring carers get the best deal out of this strategy and the best deal in the future, this is the key element that must be included.

Needs assessment must take place. It is difficult if people say that we want to care for people in their homes for as long as possible, which is the policy, and at the same time that people's needs will not be examined. This is disingenuous. Everyone is aware that needs assessment take place within the disability strategy concerning those aged five years and under. If an assessor from the HSE is assessing a disability, it would be quite simple and practical to assess the family carer and decide that the person is not trained to do the role and needs training. We often find that family carers must lift and move the person being cared for. A nurse working in a hospital would not be allowed to do that. When the older person goes into hospital, one finds two or three nurses doing the same job the carer must do on his or her own, yet the nurses would not be allowed to do it on a one-to-one basis. Needs assessment could examine these issues.

Another important point is the annual health check. Each carer should get an annual health check. This would amount to the Government and the State recognising the role of carers, understanding that carers save the State much money, recognising the importance of carers and wanting to protect carers in their role to ensure they can continue to provide the care. To do so, the State should examine the health of carers once a year to ensure that carers are in perfect health to continue the role because we do not want the carers' health to suffer as a result of this role. Research by the Royal College of Psychiatrists clearly shows that a carer's health can suffer

as a result of the caring role.



Within the carer's allowance a carer can work 15 hours per week. We would like to see that increased to 19 hours per week. The reason is that the carer would qualify for back to work schemes and community employment projects. There is evidence that the Department of Social and Family Affairs allows people to share care in terms of the carer's allowance. On that basis, they allow people to work 19 hours per week because they share the role with another carer. Therefore, they are free for the other 19 hours per week. It does not happen in many cases but there is a precedent.

The final point is quite topical. People are familiar with the comments made by the Minister with regard to carers' funding, carer's allowance and the halfway carer's allowance. The data may be subject to the review group examining current spending, spending programmes and Civil Service numbers. That group will also examine the carer's allowance, how it is spent and whether areas can be cut back. There was commentary on the half-rate carer's allowance. We want this strategy to enshrine the fact that the funding in place will not be cut and that at least we will hold on to what we have. Many in receipt of half-rate carer's allowance are in receipt of an old age or widow's pension. The level of response to the comments in the weeks since they were made has never been witnessed before by our organisation. If the issue comes to the fore, it will be larger than that of the medical card. Anybody in receipt of half-rate carer's allowance is already receiving a pension. The allowance is approximately €110 or approximately one third of a person's income.

There is a great deal of commentary on social partnership with regard to a pay freeze and pay cuts. Nobody is discussing a 30% pay cut for anybody. However, it is possibly being considered for a group working 3 million hours a week in health services and saving the State approximately €2.5 billion a year. Imagine taking action which would affect the agriculture industry. There are 40,000 full-time carers. There are also 40,000 full-time nurses. Imagine stating one third of their wages would be taken from nurses. There would be mutiny.

The difficulty carers have is that they are a hidden group. They do not work in a large hospital where politicians can have an opening day and put a plaque on a wall. They work in their own homes, which should not be taken advantage of. We are looking towards the future with regard to the delivery of a carer strategy. It is Government policy that people should be cared for at home for as long as possible. We cannot state the allowance will be taken from people retrospectively. It would be disingenuous to state we want to provide care for people in their own homes for as long as possible and also cut funding. It would be a poor day for Ireland as a nation.

Deputy Charlie O'Connor took the Chair.

Deputy Róisín Shortall:   I apologise that I will not be able to remain at the meeting. It is unfortunate that special Front Bench meetings are being held by most parties on the economic position. My party will meet next door and I must leave shortly. If I cannot stay for the reply, I will read the transcript afterwards.

I welcome the delegation and thank Mr. Egan for his presentation. I commend the work done by



the association. The total of 3 million unpaid hours of caring a week was mentioned. In its advocacy and support role the association provides invaluable assistance for those involved in caring work. I am a great admirer of the organisation. The proposals made have been well researched and grounded.



The committee has a particular role in supporting this work. We know that our predecessors on the committee made a wide-ranging set of proposals, including abolishing the means test for carer's allowance. At this stage it seems the basic demands of the Carers Association fall short of the initial recommendations made by the committee. We must keep in mind given the thorough work done by our predecessors that the committee made strong recommendations and that in spite of the economic circumstances, we should always hold these objectives to the fore and maintain them in terms of a longer term strategy for carers.

I am disappointed there has been such a delay in producing the carers strategy. It is long promised and overdue. Do the delegates have information on the likely date for its publication? As a committee, we should express concern to the Minister for Social and Family Affairs that this long promised strategy has not appeared. We should take up the case on behalf of the association and the thousands of carers who do this work. We need to be their voice and ask the Minister where is the strategy. We should also give our views on what it should contain.

The priorities identified by Mr. Egan are reasonable, even in more straitened times. He has mentioned three areas, namely, a needs assessment, an annual health check for carers and in-home respite care. We should endorse these recommendations and put whatever weight we as a committee have behind them and convey these views to the Minister. These three areas should be covered in the strategy. We should also keep the proposals which emerged from our predecessors as objectives for the strategy. As Mr. Egan stated, if they cannot be afforded now, they should still be set out in the strategy as objectives. As a committee, we should keep a close eye on developments. We should not allow the matter to drift. We have probably been remiss in the past year in not maintaining the pressure for the strategy to be produced.

I am concerned about the recent comments made by the Minister on carer's allowance. She stated carer's allowance, particularly half-rate carer's allowance, was an obvious target for cuts. I am not sure what her motivation was but she seemed to indicate that it was her view that there could be cuts in this area. I heard her trying to defend and justify it afterwards but her excuses did not wash. We must send a clear message to her that whatever cuts need to be made - there is no doubt that significant cuts will have to be made throughout the economy - there should be no question of touching carer's allowance which was so hard fought for. As well as hearing from the Carers Association about its ongoing work and priorities, we need to take up these priorities and convey our strong views to the Minister.

Vice Chairman (Deputy Charlie O'Connor):   As Senator Nicky McFadden is not present, I call Deputy Crawford.

Deputy Seymour Crawford:   I thank the Vice Chairman and welcome Mr. Egan and his colleagues. He provided a detailed explanation and the documentation presented will be of

benefit to any Member of the Dáil or Seanad who wants to read and use it.

I support the comments made by Deputy Shortall. I was a member for many of the excellent committee chaired by Deputy Willie Penrose. We fought extremely hard for the introduction of half-rate carer's allowance based on my experience and that of other members. Approximately 11 years ago I came across a case in which a young widow had to change from carer's allowance in looking after her mother-in-law to a widow's contributory pension because her husband had died suddenly. Although she could have taken any job and was capable of so doing, she remained at home to care for her mother-in-law without any support. For many years successive Ministers told us it would be illegal to make a second payment. However, in the budget prior to the last general election the allowance was introduced from September 2007. It was a welcome development. It is unreal that a Minister for Social and Family Affairs would raise questions about the allowance. It is extremely serious. The committee should do what it did under Deputy Penrose, which is to say jointly and unanimously to the Minister that this is not on, that carer's allowance is not for touching and that she must take her hands off it.

It is extremely annoying that the strategy is not being progressed. This is one area to which many others and I have been committed for a long time. I have my own family experience, but only the day before yesterday I received a telephone call from a lady approaching the age of 66 years who will soon be entitled to a pension. She was a carer for her mother and is now a carer for her father. In addition, she has a son who is confined to a wheelchair due to multiple sclerosis. The amount of money she has saved the State during the years cannot be quantified. To listen to her on the telephone expressing her annoyance at the fact that she will not be eligible for carer's allowance when she changes over to a pension was unreal.

I am interested in the service provided by the Carers Association as a body. There are no carers' resource centres in my constituency of Cavan-Monaghan, but the association obviously provides a good service in other areas.

One thing of which I am very conscious is respite care. It is a serious issue, especially for those looking after disabled young people, for whom there are no facilities available. In my constituency there are only six respite care places available. Two others were done away with recently, yet there is a brand new home, opened by the President on 17 January last year, lying empty because the HSE has failed to provide funding for staff. It was built by agreement with the HSE. I was promised in May before the last general election that staff would be in place by September, but there are still no staff in the home today.

I agree with all the comments made by the delegates about the lack of information and support available. Some individuals in the services are very good but we come across many complaints. Yesterday I heard from a person who is looking after two parents at home. Some of the equipment they previously received has broken down and they cannot get replacements. They were told it was not in their best interests to keep their parents at home, that they were nursing home cases. The Minister for Health and Children is saying we should do everything to keep people in their own homes, yet there are no back-up services. I could go on at length because this is one issue about which I feel strongly. I certainly support the final conclusions regarding

assessments and the need for support.

I am interested in the assertion that carers should be allowed to work 19 hours a week. If somebody has a disability which he or she can prove by working, he or she can get back to work. He or she is allowed to work 19 hours a week and still receive the full disability allowance. However, a carer is not allowed to work even half an hour over 15 hours. Coming from a farming background, it annoys me that a farmer's son or daughter looking after his or her parents at home cannot look after a few cattle for an hour a day without being caught by a social welfare officer who has never worked an hour on a farm in his or her life. An increase to 19 hours would be of benefit.

What is most frightening is the level of stress experienced by carers. We hear about people who are under severe mental strain. To be blunt, this is to be expected. If somebody is looking after a parent or a disabled person on an ongoing basis with little access to other activities, it is bound to have an effect on his or her mental state. People will understand and accept if they have a sore back or a sore stomach, but it is much more difficult to understand the extraordinary stress carers are under.

I thank the delegates for the detailed information they have provided and assure them from this side of the House that we are committed to retaining and maintaining support for carers. Those at the coalface in the most delicate situation of their lives should not be under financial pressure. It is those who are rich or better off who should be looked at as a means of rectifying the position.

Vice Chairman: I thank the Deputy. I should have said to our visitors that I am not Deputy Healy-Rae. I apologise that he had to leave. I am proposing to take all questions and then ask the delegates to answer them.

Senator Nicky McFadden: I welcome the representatives and apologise that my colleague, Deputy Enright, has had to leave. I am also sorry that I had to be absent. I thank Deputy Crawford for raising some pertinent issues and agree with him on all the issues he mentioned. The 161,000 carers in Ireland are unsung heroes and need an organisation such as the Carers Association to be a strong voice for them. I applaud the association on the good job it does.

The fact that the carers' strategy has not yet been published, although the Government promised to do so as far back as 2007, typifies the inertia of the Government and the disregard it is showing to carers. It is an absolute tragedy that this is how the Minister for Social and Family Affairs, Deputy Hanafin, is behaving. What consultation process has the association engaged in with the Minister about the strategy? As far back as November, my colleague, Deputy Enright, tabled a parliamentary question asking the Minister when the strategy would be published. In reply the Minister stated the Department was working on it, but it is taking a long time. The consultation process was completed in April last year. Has the association been consulted on the strategy?

The Minister's article in *The Sunday Business Post* was extraordinary. Her statement that the scheme had become costly was an insult to carers who save the State so much money. Age

Action Ireland has stated the cutting of half-rate carer's allowance is one of the biggest issues it has come across and that it has received many telephone calls about it. According to the delegates, the Carers Association has also received many telephone calls about it. It would be foolhardy for An Bord Snip Nua to cut the rate for carers. As in the case of the medical card for over 70s, I believe it is not possible to take away what is given and it would represent very bad management to do so. We will end up with more elderly people requiring full-time residential care if this allowance is cut. I propose the committee should write to the Minister saying it does not support this move and that under no circumstances should the carer's allowance be cut.

I refer to the matter of young carers, which was not mentioned in Mr. Egan's presentation. There are 5,000 young carers in the country. Has there been any recognition of their work by the Department? The allowance of €214 does not amount to the minimum wage. Can the delegation comment on the small amount of money carers receive and how best to adequately support carers? It was mentioned that carers have no entitlement to a pension and that they cannot contribute to the State contributory pension. They do not pay PRSI stamps. What is the view of the delegation on this matter?

Respite care was mentioned. My colleagues are acutely aware of the work of carers in this regard. Research carried out has revealed the stress and strain on the mental and physical health of those involved. How does respite care work? It is unclear to me and the service seems to differ from county to county. I thank the delegation for its presentation and I would be delighted to do anything I can to help.

Vice Chairman: I intend for the committee to go into private session for a short period. This would allow us to reach agreement on a letter to be sent to the Minister expressing the view of the committee. We will also provide a transcript of the meeting to the Minister. I hope the committee will agree to this unanimously, but we must decide on the matter in private session and I hope I have the support of all colleagues in that regard.

Deputy Thomas Byrne: The association raised other matters also relating to the carers' strategy.

Vice Chairman: The delegation may wish to note that I propose to proceed in this way.

Deputy Joe Carey: I welcome the delegation and I thank it for a very good presentation. It has put together an excellent document which clearly sets out everything related to caring, carers, the problems encountered and the objectives to be met. The work of carers is invaluable. They spend 3 million hours every week looking after families and loved ones and because this work takes place behind closed doors people cannot see the value of their work. The State should recognise this fact.

It was shocking to hear the Minister for Social and Family Affairs comment that the half-rate carer's allowance was an obvious target for cutbacks. It was appalling for the Minister to lead the charge on that matter. I received many phone calls from carers and their families who have been subjected to pain and distress because of the comments of the Minister. If the committee is to be

relevant it must send a clear “hands off” message to the Minister regarding the half-rate carer’s allowance.

Senator Nicky McFadden: Hear, hear.

Deputy Joe Carey: Carers should not be a target and the Government should have learned lessons from the medical card debacle. I welcome the Vice Chairman’s intention to formulate an agreed approach on this matter and to take a strong stand. It is important that the national carers’ strategy is published. It has been put on the long finger and it is obvious that it must be published. We must have an input in that regard. I agree with Deputy Shorthall that the objectives and the key recommendations of the delegation’s report should play a role in this matter. The objectives and recommendations of the delegation should be included in the report.

Deputy Thomas Byrne: I second the suggestion of the Vice Chairman that the committee should write to the Minister on the very important matter of the half-rate carer’s allowance and on the national carers’ strategy. Some members had the opportunity to meet the association before Christmas. It raised several issues which should figure in the letter the committee sends. The committee should clearly indicate that carers are very valuable. At present my grandmother is cared for by a relay team of family members. There are similar arrangements in families throughout the country, which saves the State considerable amounts of money, because subventions and nursing home beds are not used in such cases. All families have connections to carers. They are very useful for the economy and the carer’s allowance provides savings in the area of home help. Home help is considered very valuable also. I echo the comments of the Vice Chairman and if it is appropriate the committee could send a copy of the letter to the association for its perusal.

Vice Chairman: We can also ensure that when the Minister responds to the committee, the response will be available to the association.

Deputy Catherine Byrne: I thank everyone for attending the meeting. I am very pleased to have had the opportunity to hear the views of the association. It is almost unimaginable to consider how the hospitals and nursing homes would cope without the work of thousands of carers. The services are bad enough at present, but it beggars belief to think the situation could be worse. I am sorry that by 2025 we will all be somewhat older and will need help, including the Vice Chairman, Deputy Charlie O’Connor. Hopefully the assistance will still be available.



As a public representative, I have visited many houses with families who have expressed concern about elderly parents and young children requiring carers. At first I did not realise the extent of the problem, but then my mother took ill. She is 88 years of age and is now being cared for at home by my brother. It is only in recent weeks, as she has deteriorated, that the responsibility of her care has shifted to the rest of the family, because my brother was quite ill during Christmas. We were all obliged to get into the boat and start rowing. It is only now I realise the inadequate nature of the services.

Let us consider a typical example. My brother spends most of his time washing sheets, blankets and everything else. His ESB bill rose from an average of €180 per month to approximately €400

per month. That gives an indication of the services he provides and the cost to him as a carer. I spent some time last week looking for incontinence sheets. Anyone caring for an elderly person at home will know of these. The health service nurse told me the HSE no longer supplies them to family homes as they are considered a fire hazard. I am not sure what she meant. However, they are no longer supplied by the HSE, with the result that I spent several hours trying to find out which company would supply the sheets. I then found out to my horror that they would have to be paid for. The average cost for 200 sheets is €100 and the supply runs out quickly. Sometimes as many as five sheets are used per day. I am concerned about the extra costs this puts on my brother and other carers. He only receives half of the allowance. What struck me most, while being involved in caring for my mother, was the emotional effect it had on a family which included having to stand in the shower to wash my mother in the morning. I understand why my brother was so ill when he went through the process before Christmas because it was a huge strain on him as the rest of the family are only now beginning to realise. We all have our own families and do our own thing, and caring is left to the person living with the parent. There is an onus on us, not only as family members but also as public representations, to make sure this service which is needed is not cut back in any way. The problem is that the services needed in the community are not available. One example is that one is unable to get proper sheets for a bed. It is outrageous. If my mother is sick during the day, we have to call her GP who must come from Tallaght. He is very good but it is an extra burden on him and takes him away from his clinic. There should be a service a carer can call to ask for advice over the telephone from a doctor or nurse.



The members of my family consider that training on how to deal with our mother is needed. Lifting, changing and washing her have become big issues. We are wondering if we are doing what we should be doing. There is, therefore, a need for such a service. Perhaps someone could come and guide us on how to lift her and other issues. As a person involved in her daily care of mother, we do not know how to lift or feed her. Every person caring for an elderly parent needs such guidance. I appreciate what has been said and have no problem in supporting the priorities outlined by the delegation. Little things can make life much easier for a person caring for an elderly parent or a child in the community. We need to focus on this. The Minister knows about the bigger issues which do not need to be raised. There are matters such as the loss of incontinence sheets in regard to which someone should be able to make a telephone call to ask for advice.

I fully support the Carers Association. I have been a public representative for many years. My mother says it is in eating a pudding one realises the contents. We all agree that caring for someone 24 hours a day, seven days a week is a huge responsibility. There would be a real crisis without carers. I thank the delegation for its presentation which was very worthwhile.

Senator Larry Butler:   I welcome the Carers Association and its report. It is an excellent document which sets out clearly what carers do and highlights their importance. They should be thanked for the wonderful work they carry out with no fuss. They ensure older people and others who are not fit to look after themselves are looked after. From a financial point of view, it provides the best value for money compared with all other services. It keeps people out of hospital and in the home where they should be and want to live. People do not want to live in a nursing home or hospital but in their own home if they can. Most can do so as a result of the

good services provided by the Carers Association. We must value these services more. The delegation will agree that when scarce resources are under pressure, we must try to get the best value for money we can. However, sending the message that these services should be cut is wrong. We must maintain and improve existing services when we have the resources to do so, as the State is getting good value for money.

We are in a situation where we will all have to work together. The Government is not alone. Everyone will have to put their shoulder to the wheel. If the Government followed the example shown by this group, this would be a better country and a more caring place. The Celtic tiger has left us which, in many ways, may be no harm, as we all got carried away by wealth and profits and forgot about the most important things in life. We need to support older people to whom the Carers Association is delivering a service. No matter how bad things get, we must maintain that service. I agree with the Chairman. A message must be sent from this committee to ensure we support the work being done by the association.

Vice Chairman:   I wish to be associated with the welcome extended to the delegation. Deputy Byrne mentioned Tallaght. In my work I frequently meet colleagues in Clondalkin and I am delighted to applaud the efforts being made. There is strong cross-party support for the work being done. It is genuine because all public representatives come across issues on the ground. There will always be issues on which different political perspectives will emerge.

Mr. Frank Goodwin: I am chairperson of the Carers Association and thank the committee for allowing us to put the case before it. I will begin by discussing the carers strategy. A commitment was made, in the social partnership agreement, Towards 2016, that it would be ready by December 2007 but I understand work on it had not even started by then. We were then told that it would be ready by mid-2008, with the proviso that this was not guaranteed but that an effort would be made to have it ready by that date, or by the end of 2008. I understand the current status of the document is that most, if not all, of it has been drafted. At this point it goes into what can be called the political arena and will have to go to each Minister concerned with its content. They will engage in a final writing and it will then be brought back to the Government. I do not know how long that will take or for how long it will be deferred but it is a source of serious concern for us.

Another serious concern is that the Civil Service has dampened our expectations each time we have met it of late. We are being told to lower our expectations which I do not think are very high in the first place. We are pragmatic. Without elaborating in great detail, I will tell the committee what our expectations are.

My concern is that the strategy will not be worth the paper it is written on if the unofficial feedback we are receiving is accurate. It has been couched in terms associated with the current state of the economy, but I do not buy into this. I have no problem buying into the reality of the current state of the economy, as anybody who does not know there are serious problems in the economy is living on a different planet. I set the Government's proposed strategy in the context of what it has said, namely, that it is and has been for years its strategy that people with disabilities, a serious or terminal illness, etc., should be allowed and supported to stay in their

own home if at all possible because that is where they want to be and with its ethos where our society says they should be. Therefore, this is a priority.

The Government has to spend money to maintain and develop services. It will define, as any responsible government would, its priorities during these difficult times but this should be one of its priorities. It is already seeking to achieve another priority, that of cutting back on what it considers to be wasteful and unproductive hospital services to phase out services that are not needed and to provide better centralised services in larger regional hospitals. Unfortunately, smaller hospitals are being closed and money is not being made available to replace services with better ones in regional hospitals. A consequence of this is that someone is picking up the slack for what has been cut out of the system. The carer group is a key element in this respect.

Where previously one would have had one's relative admitted to hospital to receive acute treatment such as an operation, effectively the system is now saying the service is so costly that the person concerned should only go into hospital when the medical staff are more or less ready to wheel him or her into the operating theatre. Patients should not be convalescing or occupying a bed for days on end when no procedures are being done other than the odd test. A person should be brought in, tests undertaken and the results given; he or she should then be brought into the operating theatre to have the operation performed and then moved on to allow the next patient to move in.

That is a reasonable approach in dealing with a high cost specialised service but a repercussion of this is that a carer is caring for a person in a more dependent state because he or she is progressively becoming ill. The carer has the person concerned in his or her home for longer. Also the carer has the person concerned during the convalescent period when he or she has a higher level of dependency. The problem is that carers provide such care without the support services needed. Even with support services, a carer still provides 80% to 95% of the care needed. He or she administers the medicine, diagnoses the effect on the person being cared for and determines whether it is working. GPs do not check up on patients; the carer has to telephone the doctor when such a visit is necessary, or to advise that the medication prescribed is not working and that the person concerned does not seem to be getting better. A carer does these jobs, in addition to providing the hands-on care Deputy Byrne described such as bathing, feeding and washing.

The implementation of the strategy is urgently needed. The strategy is a statement of policy and, I hope, the actions the Government intends to take. Its production is urgently needed. This should rank as a priority, even in these stringent times, as there will be an increase in the number of dependent people due to the age structure of the population. Therefore, the production and implementation of the strategy should be seriously addressed.

Given that carers provide vital social and health care for their relatives and such care forms such an important part of health and social services, they should be supported in an incremental way. There should be no question of withdrawing half an allowance from them. That would be nothing more than a financial exercise. The people concerned have already been assessed as providing full-time care which they will continue to provide, irrespective of whether they are given half an allowance. It is a serious matter to withdraw from them one third of their current

income while they continue to provide 24-hour care. Carers provide care for more than 3.5 million hours a week, which amounts to the equivalent of a modest pay rate of approximately €13 an hour if they were working in the paid sector of the economy. It is easy to multiply the number of hours worked by carers, details of which were given in the last census and the cost of which works out at more than €2.5 billion per annum. I draw these figures to the committee's attention.

We are very aware of young carers. The Department of Health and Children has commissioned research through the University College Galway to gather further information on this aspect. It is particularly difficult to find hard core statistics and information. We have some figures from the census but they are not comprehensive by any means. We hope this research which I understand will be carried out and completed this year will throw up some valuable indicative information. Many positive actions could be taken in regard to young carers by focusing on projects through schools which are aware of young people who miss out on school work due to absence from school. They are tuned in to young people who fail to produce homework and do not have a good school attendance record. The normal maturation process young people need to go through is affected by the fact that they carry out of adult tasks and miss out on the socialisation process. We consider schools to be a vital channel through which to gain information and help the young people concerned.

Another aspect of carer's allowance the committee should bear in mind is that more than 40,000 carers ticked the box relating to the provision of care for 43 hours or more a week, some of whom work probably double that number as they provide supervision and companionship throughout the remaining hours. Some also provide night-time care. They may have to attend to the person concerned during the night who may be suffering from dementia and roam within the house, or they may be looking after a person who is fully *compos mentis* but owing to his or her disability and medical condition needs active intervention. It is important to bear this aspect of care in mind.

On the new criteria that will apply in qualifying for a pension, we are deeply concerned that carers on reaching 66 years of age will find that they will not qualify for a pension in their own right, in other words, they will be subject to a means test to determine if they qualify, despite the fact that the State recognises that they are full-time carers, working in the home. They would not be in receipt of carer's allowance unless they were working in the home, providing full-time care and it had been medically certified that the person they were looking after required care. The State is effectively saying it does not recognise this work as contributing towards a carer's pension entitlements, which is an appalling indictment of our society. That is the reality and such an entitlement is obtained more by default than anything else. The criteria need to be put right, with an element of retrospection for those carer who will reach pension age this year, next year or in the next few years.

I will hand over to Mr. Egan in case he wishes to add to some of the points mentioned, including that of respite care. Deputy Catherine Byrne clearly outlined the appalling situation regarding incontinence pads. People may be obliged to wear incontinence pads due to their illness or perhaps, in the case of frail older people, their frailty. Great difficulty arose in respect of the pads even when they were available but at least they were available in some form. People now are

obliged to source them and one finds that the health service and many statutory services are very slow to indicate where one can procure items such as pads to avoid being accused of favouring one firm over another, which would not be perceived to be correct in respect of our private sector. One is then left in the position whereby one must find out who supplies such items, where they are and how one gets them. One must so do even before starting to consider how to pay for them and thereafter, one must pay for them. Basically, this is a double whammy in which people who are sick are told that were they in hospital, they would not be obliged to pay for such items but as they are not, someone within their household will be obliged to pay for and source them. This is a blow, to both the person who is receiving the care and the carer, that should not be tolerated in our society.

Mr. Enda Egan: I will wind up by making a couple of broad comments. First, I refer to Senator McFadden's question on the potential impact of changes to the half-rate carer's allowance. From the numerous telephone calls we have received in recent weeks on this issue, it is clear that family carers have built the €110 into their weekly spend. This money is being spent on items such as ESB and heating bills, which, as has been pointed out correctly, go through the roof. I refer to the cost of care, which means that if one compares a family in which no one has health problems to one in which someone, such as an older person, has a health problem, a great number of family costs go through the roof. I refer to items including heating, transport and specific nutritional items, such as special dietary foods, which cost a lot more, and to medical bills that are not normally covered in particular. A great number of additional expenses must be covered and this is where this payment has been directed.

Last week, we heard from a number of people who called into radio programmes. They were predominately women who were either pensioners or widows. Their cases matched those described at this meeting, whereby, for example, a person may be looking after her husband's mother, the husband having passed away, leaving the carer on a widow's pension. Such people now get the half-rate carer's allowance and some people have told us that were this money to be taken away from them, it would oblige them to turn off the lights earlier and use less heating and would mean that bread-and-butter or everyday living items must suffer. That will be the impact. Ultimately, this would affect ordinary people's lives and would constitute the imposition of a 30% cut on the income coming into the homes of the most vulnerable people when, at social partnership level, much smaller wage cuts, if any, are being proposed.

I refer to the other points made by Senator Butler, which are of huge importance. Care is provided on the cheap in this country as 90% of community care is provided by family carers, rather than in the major hospitals or the big buildings one sees in towns. Such care probably is the best value for money available and the Department of Finance should conduct an exercise on it to ascertain its value. Of course, such an exercise has not happened as people want to steer away from it because they do not wish to put a spotlight on it. However, such care is extremely valuable and is worth €2.5 billion to the economy, which equals the worth of the farming sector. This is a huge resource that must be protected and we must approach it from that point of view.

To recap and to follow up on the points we made previously, the Government must come to the table in a fair and honest fashion. As Mr. Goodwin noted, up to a point everyone will understand that we are in an extremely serious economic position which must be considered and about

which certain measures must be taken. However, priorities also exist and given this country's direction, both dynamically and from a demographic point of view, more people will require care in the future and fewer people will be available to provide such care.

Although our stated policy is that we wish to provide care for people in their own homes for as long as possible, at present the value of the nursing home subvention is greater than the carer's allowance. Moreover, under the new fair deal that is going through the Dáil at present, it is proposed to increase it to €800. In other words, the Government will provide that amount of money to enter a nursing home. While it may take back up to 25% of the value of one's estate, such a measure will be put on hold until one passes away. At the same time, however, we are discussing taking €110 on a weekly basis out of the pockets of those people who are delivering Government policy. The nursing home situation is not delivering Government policy. While nursing home care unquestionably is a vital part of the required mix, our policy, rhetoric and our practice must be much better and closely aligned.

As for the strategy, it must be made clear that if certain matters will not be dealt with now, they must be named. The strategy must state clearly how we would like to deal with them now and that they will be brought back to the table under each review as they take place. As for needs assessments and annual health checks, such initiatives have been done on a pilot project basis in the United Kingdom. At a time like this, when we are under pressure economically, perhaps a strategy such as this should include many pilot projects. Perhaps the Government should state that although it would like to roll out a particular measure on a national level, it does not have the money to do so but that, nevertheless, it will do its bit by running a number of pilot projects to test the measure to see how it works and to learn from it. That would be a fair and honest approach and would allow people to acknowledge that although the money is not available at present, the Government wishes to help them out in this regard and at least is doing its bit. Were this to be included in the strategy, people would be able to state that at least it is fair and honest. Were it to be left out, as it appears may be possible, people could only judge that our policy and rhetoric will not run in line. Were members to consider supporting such an approach, it would be highly supportive.

I ask through the Chair, if possible and if there is time, that our family carer who has accompanied us might address the joint committee.

Vice Chairman: Deputy Mattie McGrath has just indicated that he wishes to speak briefly. Thereafter, I will facilitate Mr. Egan's request.

Deputy Mattie McGrath: I will not speak at length. I thank the Vice Chairman for the opportunity to speak and apologise for my sporadic attendance of the meeting but I am involved in another committee meeting next door. I met representatives of the Carers Association before Christmas and completely understand their perspective. I compliment the witnesses on their presentation and on the work they do. While I do not wish to be repetitive, I fully support what they seek, fully support the Vice Chairman's proposed actions to be taken after the meeting and will press the Minister. Certainly, we should hold what we have and should try to move towards improving the lot of carers.



Vice Chairman:   Mr. Egan should introduce his colleague.

Mr. Enda Egan: I wish to introduce Ms Mary McDonnell, who is a family carer from Cork who looks after her daughter.

Ms Mary McDonnell: I am Mary McDonnell and I am 71 years of age. I care for my daughter, who suffers from spastic quadriplegia. She is doubly incontinent, has a dislocated hip and severe scoliosis. My job entails working all shifts because my daughter's condition has greatly worsened in the past year. All carers welcome the Government's commitment to the delivery and implementation of a long overdue national strategy for carers. The speculations by the Minister for Social and Family Affairs, Deputy Hanafin, really alarmed me and my fellow carers. It really upset and distressed us, and made us very angry. This strategy should not be watered down and the current economic times should not have any effect on it. It should be delivered in full.

First, a needs assessment should be conducted. This would be a necessary part of the strategy because we must have our needs identified. This then should be followed up not with discretionary supports and services as we have had down through the years, but with rights-based services and supports. Several members raised the issue of respite, which also is completely inadequate, as are all the other community services. In each of the past ten years, for instance, I have received five two-week respite care periods in respect of my daughter at Cheshire Homes. Through lack of funding, this service has been reduced to two two-week periods annually. For the past ten years, there have been three HSE-funded respite beds. That number will remain the same in 2009. Demand far outstrips supply. This is wrong because there should be no reductions in our services or supports.

Regarding the half payment of which I am in receipt, the speculations of the Minister, Deputy Hanafin, alarmed and upset my fellow carers and me. Hands should be kept off the services and supports. Instead of saying that they might be cut, our strategy should be delivered in full. We need it and it is ours by right.

Vice Chairman:   I thank Ms McDonnell for sharing her thoughts. Would one of the witnesses like to sum up? I am not saying "Goodbye".

Mr. Frank Goodwin: That is all that remains, as we have given the committee a thorough picture and do not want to delay it further. I thank the Chairman and the committee members for allowing us such a fair period in which to present everything. As Mr. Egan stated at the beginning, the committee is aware of carers' situations.

I was taken by Deputy Catherine Byrne's comment about the way in which carers' issues have progressed, as it also struck me. If we do not accelerate the process of delivering services and rights, a satisfactory level will not be reached for another 20 or 25 years. I might be left out of the game because I will probably be dead by then, as might some others in attendance. We will be the lucky ones. The rest will either be in receipt of or providing care. This is the reality of life for us all. We should take it on and address the issues as best we can. I thank the committee.

Vice Chairman: I was just looking at my colleagues to determine who it could be. Deputy Catherine Byrne's remarks remind me that my sisters will send me to a home in her constituency if they can.

I thank our guests. At a time when there is a debate on the workings of the Dáil and joint committees, this morning has proved that the latter have a role to play.

Senator Nicky McFadden: It depends on how well we get along with the relevant Minister.

Vice Chairman: Yes, but we should not underestimate the importance of groups attending meetings and sharing with us views that many of us on the ground understand. I thank our guests on behalf of members and the Chairman, who unfortunately needed to leave, for giving such a comprehensive outlook. I propose that we agree to convey all of those opinions to the Minister.