

Chairperson's Foreword

There is an urgent social and political necessity to address the injustices of the Family Carers position in Irish society.

There are 150,000 Carers in Ireland working over 3 million hours every week resulting in savings to the Exchequer of up to €2 billion each year.

Family Carers are the primary health and social practitioners implementing government policy, which is to care for people in their own homes for as long as possible. They ensure that our children and adult relatives of all ages who have special needs, who are disabled or who are extremely frail receive the special and intensive supports to remain living in their own families, in their homes and communities.

The Family Carers work is not matched by the statutory sector. There are glaring deficits between government policy on the one hand and statutory practices and services on the ground. In addition Family Carers have no rights or protections in Irish Law in relation to the caring work that they do.

Family Carers have gone through the learning curve and it is now time to introduce a National Family Carers Strategy. It is now time to recognise and deliver on essential support services, based primarily in the home and immediate community. It is time that Family Carers are integrated in the paid service sector labour force and receive the recognition and remuneration for the essential societal work we are providing.

The Carers Association now calls on our government and social partners to declare this issue a priority in 2005 with specific targets to be implemented over a clearly defined time frame in the context of the next Social Partnership Agreement. The Carers Association are members (Community and Voluntary Pillar) of the current Agreement Sustaining Progress.

Frank Goodwin, Chairperson.

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General Context and Rationale

Definition of Family Carers

Family Carers are people who provide high levels of unpaid care at home for children with severe disabilities, adults with special needs, frail older people and people who are terminally ill.

Family Care Profile

The Census of Population 2002 indicates that there is a total of 148,754 Family Carers in Ireland, appearing in every age group, predominantly but not exclusively female and living in every county. A total of 40,526 Family Carers are providing full time care of 43 hours or more per week, while the number of part time Carers amounts to 108,228.

Caring for people in all age groups

Carers are maintaining people of all age groups at home, from infants born with illnesses or severe disabilities to people who become frail and require support later in life. Many Carers are providing care for their own children from infancy right throughout their lives. In middle age Carers are concerned with Family responsibilities, mortgages, employment and combining these with providing care for their child with special needs. In old age Carers worry about the future of their adult offspring and who will look after their son / daughter when they are deceased. Many older persons are Carers for spouses, brothers or sisters, at a time when they should be working less and looking after their own health. There is in addition the phenomenon of children caring for parents with disabilities.

Working conditions of Carers

Carers need to be constantly available due to the high levels of social and health care needed at home, and in case of emergencies. The Carers life centres on the needs of persons requiring care. Interpersonal support, companionship and love are the essence of the Carers presence. Carers are frequently carrying the same responsibilities as a team within a nursing home or residential setting, providing high-level support, without the benefit of expert training, normal working conditions and supporting colleagues. For example, it is the sole responsibility of the Carer to ensure that medication is taken, at

appropriate times, and to monitor the outcome and contact the medical and nursing professions when the Carer judges necessary. Changing dressings, bathing and assistance with all personal care needs, which are specialised tasks in welfare and nursing homes, form the daily routine of Carers work. Some Carers are providing a daily service to more than one person. Carers who are employed outside the home have to combine this with evening, night-time and weekend caring which is often intensive.

Contribution of Carers

Every week some 148,754 Family Carers spend more than 3 million work hours doing caring work. This enormous input into our economy in terms of services provided to citizens who require extra support in order to live in their own homes is essential primary work. This core societal work is not regarded as part of the GDP of the nation, in marked contrast to the paid service sector. Should Carers stop this provision then large numbers of children, older and disabled people would have to move into residential care or paid home help and home-nursing staff would be required to meet the needs of those receiving the home care. Full time Carers, like anyone who works long continuous hours, are vulnerable due to the stress and strain of the work conditions. These conditions constrict the Carer's other life interests, which are essential to maintaining a healthy lifestyle. In practice there are Carers every year who cease providing care because they cannot cope any longer due to the work conditions and pressures in the home and, as a result, their relatives have to move to long term residential care.

Government Policy

It is government policy that people with disabilities, people who are frail in old age and those who have long-term illnesses should remain in their own homes and communities, as this is their wish and that of their families and friends. There is a core conflict in government policy as regards Carers in Ireland. On one hand, the achievement of very high paid-employment rates is at the centre of government policy and everyone is being encouraged into the paid workforce, including Carers. On the other hand, Family care remains the bedrock of health and social service policy and service delivery, with an expectation that Family Carers will continue to provide the bulk of care in the home.

With inadequate investment in essential support services and inaction on the work conditions of Carers, the situation is becoming increasingly untenable and is resulting in ill health and unacceptable living standards for many Family Carers. The reality is that the situation of

Carers is much more difficult because respite and other community-based services are insufficient to meet current needs.

Why a National Strategy?

Against this background there is a pressing need to develop a comprehensive strategy for Family Carers in Ireland. Such a strategy must recognise the economic and social importance of family care and provide the necessary supports to enable it to remain sustainable without undue costs for Carers. Carers must be fairly recompensed for the significant losses of income that arise when they remain outside the paid workforce or reduce working hours due to caring responsibilities.

Caring can be enriching and rewarding work, if the expectations placed on Carers are reasonable and Carers are properly supported. We need to ensure that policy focuses on the human and social dimensions of family caring. Caring is an expression of familial, social, societal and inter-generational bonds and relationships, and is one of the core expressions of the social capital of communities and societies. People must be allowed the opportunity and be facilitated to care.

A National Strategy

Objective

To develop a comprehensive national strategy for Carers in Ireland

Actions

- Establish an interdepartmental task force to manage the formulation of the strategy and present the strategy to cabinet within 2005.

A comprehensive National Strategy for Family Carers in Ireland is required in order to give full and formal recognition to the societal importance and economic value of the caring work that is being done by carers.

The development of a national strategy to ensure a fair deal for Carers is a justice, equality and an economic imperative.

Such a strategy must address all of the issues in a comprehensive and co-ordinated manner. In particular, there is a need to:

- develop a support system for Carers that takes account of today's realities for families, where employment income and often two incomes in a household are a must for an adequate living standard;
- give formal recognition to the societal importance and economic value of the work that is being done by Carers and have it placed as an integral part of our health service;
- anticipate the implications of demographic change down the line for the provision of family care in the home and its knock on effects on our Health services;
- provide appropriate measures to allow carer participation in the paid labour market where appropriate and feasible;
- recognise that Carers working in the home require the same supports and protections as paid workers;
- extend the role of the State so that it takes more responsibility for care in the home and the community;
- encourage employers to contribute to a family care dimension within the workplace through the adoption of flexible policies;
- promote awareness and discussion among family members to achieve a more even distribution of care required;

- address the contradictions between full employment policies, on the one hand, and an expectation that Family Carers will carry the primary responsibility of care, on the other.

Developing a National Strategy For Family Carers: Need for A Co-ordinated Approach

As the issues arising for Carers holds interest for a number of Government Departments, representative groups, and other organisations a co-ordinated inter-departmental and inter-sectoral partnership approach is needed in order to develop an effective and comprehensive national strategy for Carers. The following should be represented, The Department of Health and Children, The Department of Social and Family Affairs, The Department of Education and Science, The Department of Enterprise Trade and Employment, Social Partnership Forum and Carer's groups.

A National Strategy for Family Carers: Key Components

A National Strategy for Family Carers should have the following six components:

- Comprehensive services and supports for Family Carers;
- Enhancing and supporting Carers' health and well-being;
- An adequate and fair system of remuneration for Carers;
- Education and training for Carers;
- Work-life Balance policies that support Carers;
- Access to up-to-date and accurate Information.

The following sections outline what needs to be addressed within each of these key components.

The provision of Services and Supports for Family Carers

Objective

To encourage and help sustain Family Carers in their roles through the provision of an adequate range of services and appropriate supports

Actions

- Prepare and implement a comprehensive Needs Assessment protocol for Carers and those that they care for, to be used to identify the range of services and levels of support to be provided
- Ensure that practical and social considerations, as well as health ones, are taken into account in Needs Assessment
- Appoint key workers whose role is to carry out the Needs Assessment and to manage the support packages put in place.
- Provide the necessary resources to increase the capacity of the current publicly provided home care and community day care services to meet demand
- Implement measures to stimulate private supply of such services and regulate the quality of privately supplied services
- Increase the availability of home and day care supports whilst Family Carers are at work and organise such services in a manner that fits with the requirements of working Carers, for example hours of availability
- Expand the range and availability of respite services (home-based and residential) to enable a flexible and responsive service to be provided that will help sustain the capacity to care and maintain the health and wellbeing of Carers
- Introduce a specific counselling service for carers, as many carers may experience emotional difficulties particularly at the beginning and towards the end of a Carers role.
- Provide the necessary resources to establish an adequate level of Carers support groups.
- Give more attention to the role of assistive technologies in supporting carers, including the new developments in areas such as "smart homes" (The use of modern technology to assist the living environment within the home)

Apart from financial aspects, Carers need a variety of services and supports if they are to be able to sustain their caring roles, provide high quality care and maintain their own health and wellbeing.

The Facts

Services for Carers in Ireland fall far below international good practice

- Unlike other countries such as the UK, Irish Carers do not have a right to Needs Assessment in relation to their own needs
- The numbers in receipt of home care services in Ireland are about one quarter of those in countries such as Denmark
- Studies in other countries, such as the U.K., suggest that Carers need regular, on-going respite if they are to be properly supported in their caring role
- Availability of technologies for home care, such as basic social alarm services, falls far below that in many other countries

Needs Assessment

Initially Carers must be identified so that their needs can be assessed. This requires increased awareness about Carers especially amongst health and social care all professionals and other service personnel and the implementation of systematic procedures for identifying Carers and referring them on to the appropriate services. Those with key roles to play in this include: general practitioners, public health nurses, discharge personnel in hospitals and staff involved in assessment of applications for social or community welfare payments such as Carers Allowance and Domiciliary Care Allowance. Voluntary/Community Organisations also need to be actively involved as in practice they frequently provide the services.

A comprehensive Needs Assessment must be available to all Carers as an entitlement. This should be more than a once-off event as needs change over time and periodic re-assessments are important. Initial assessments should be as early as possible, to prevent health or social - problems arising or to pick them up before they progress too far. The scope of the assessment should be comprehensive and not restricted

solely to needs for services that are provided through the public system or currently available

Access to public services or to financial supports for private purchase of services should be based on appropriate and standardised Needs Assessment criteria and procedures. In the UK, for example, Carers have a statutory entitlement to a Needs Assessment in their own right and there are currently proposals to include the employment or training situation and / or aspirations of Carers within the Needs Assessment and the allocation of services.

Respite Care (Home based and residential)

Respite care is essential for Family Carers. Respite care services should be available as of right and in a planned and systematic manner in total contrast to the present system where availability in many instances is haphazard and piecemeal.

- Both full time Carers and Carers working outside the home need access to adequate respite care services, offered in a flexible and responsive manner.
- Such services are needed to take over the caring responsibilities so that Carers can take a break, go out in the evening, get a good night's sleep, take a holiday or attend education or training.
- Respite services should be available both in the home and outside the home to cater for different needs.
- Respite services are also needed to facilitate people who have to or want to work outside the home.
- Respite care for emergency situations is also essential.

Opportunities for respite are currently very restricted in Ireland and need to be substantially expanded. There is a need for substantial expansion of such services, tailored to meet the needs of both full-time Carers and Carers working outside the home.

Access to Health and Social Services

There is a need to ensure that Carers and those that they care for have access to all necessary levels of the health and social services. There may be a particular difficulty in gaining access to relevant specialists due to geographic locations. A case in point would be an appointment with a geriatrician because of where the elderly person lives; they may never be in a position to have a consultation. Home visits by general practitioners are another important requirement, but these have become increasingly difficult to arrange.

More generally, there is an array of services and supports that can have importance for Carers. These include occupational therapy, Carer support groups, home nursing, physiotherapy, social worker support, counselling, chiropody, as well as home adaptation. Assistive technologies and telephone-based alerting systems also have an important role to play. There are now various low cost “smart” devices and systems that can be very helpful for Carers, and these should become a mainstream part of occupational therapy and home adaptation services.

Key Workers

There should be provision for key workers who would take responsibility for the whole case (comprising the Carer and the person being cared for), co-ordinate their care and ensure access to all necessary services. The key worker¹ role would require a broad training and awareness of needs. In other countries, this function is often filled by social workers and there is a case to be made for expanding the availability of social workers to fulfil this role in Ireland.

Input of Carers

The design and delivery of services for Carers should be informed by the views and practical expertise of Carers themselves. There are two levels at which this is required. In terms of overall policy and service development, Carers need to be formally represented in the consumer panels and other consultative mechanisms that are being implemented by the health authorities. In addition, Carers should be given formal recognition and a formal role in the management of care services for the person that they care for.

¹ This key worker role is *not* the same as the current Health Service Executive carer co-ordinator role, which operates at an overall service level and not on a case-by-case level.

Availability of Services

Universally available publicly-provided respite, home care and day care services would ensure that all Carers had equal choices as regards working, caring or a combination of the two, as well as ensuring that caring roles were sustainable for Family Carers. If, instead, a mix of public and privately purchased care is to be encouraged, then there is a need for the private care service sector to be developed and regulated in Ireland.

Carers' Health and Social Well-being

Objective

To ensure that the health and well-being of all Carers is adequately addressed

Actions

- Develop a health and social risk assessment measure appropriate to the Carers work environment.
- Provide training courses in skills required, based on Needs Assessment of recipient of care.
- Provide appropriate equipment and home adaptations, based on Needs Assessment and carers work conditions.
- Provide all full-time Carers with medical cards to include one annual comprehensive health check
- Establish a publicity campaign to promote awareness among Carers and health sector personnel about the importance of Carers looking after their own health and well-being. This must include age and work related alerts.

Carers often overlook or suppress their own health, caring and well-being needs in their concern to meet the needs of those who are being cared for. There is much evidence that caring can have detrimental impacts on Carers' own health and well-being. If Carers end up in poor health they are unable to provide care, and some will require care themselves.

The Facts

Carers are at risk of poor physical and emotional health

- Research by the South Eastern Health Board (2000) found that a significant proportion of Carers reported deterioration in their health subsequent to taking on a care-giving role.
- Research by the ESRI found that Carers were at higher risk of anxiety and depression (Blackwell et al., 1992).

- The physical aspects of caring, for example lifting, can have direct consequences for health, and many Carers develop back pain and other conditions as a result.
- Caring round the clock and chronic disruption to sleep can be a cause of serious health problems.
- The constant stress, worry and emotional upset can have negative impacts on both physical and psychological well-being.
- Ineligibility for a medical card can mean that the financial costs of attending a doctor are a deterrent to Carers seeking help.
- Taking on the role of a Family Carer is often the result of a situation where there is little choice and, therefore, people frequently end up caring without realising about what it entails.
- Caring is challenging and difficult for many people and this needs to be recognised in the support systems that are put in place.
- Many Carers are themselves elderly and sometimes in poor health. Their needs must be given particular attention or they may end up requiring care.
- There are many young Carers, teenage or even pre-teen children caring for a parent. They need special help, advice and support in dealing with the emotional and social consequences.
- Carers who must provide round-the-clock care are at high risk of health consequences, as are those who are caring for people with severe learning disabilities or people with conditions such as dementia.

Despite these important health concerns, Carers in Ireland are not currently considered as clients of the health and social services in their own right, with their own needs for assessment and for appropriate care and support. This is in contrast to the situation in other countries (for example, the UK) where Carers have a statutory entitlement to Needs Assessment in their own right.

A concerted effort must be made to bring services for Carers in Ireland up to the best international standards. This requires the establishment of procedures for identifying Carers and assessing their needs, and the provision of the necessary services and supports to meet assessed needs.

Carers' Needs Assessment should look at all aspects of the Carer's health, including both their physical and emotional well-being. The assessment should take a holistic perspective, including issues such as healthy diet and lifestyle and a health and safety audit of the caring situation in the home.

The needs of carers should be addressed through training, counselling and help with developing coping mechanisms, including ensuring a balanced lifestyle that is not completely dominated by the caring role.

Awareness-raising amongst Carers themselves is also necessary, to alert them to the need to look after themselves and to encourage them to get advice and support.

An adequate and fair system of Remuneration for Carers

Objective

To ensure that payments to Carers are commensurate with the value of the work that they do including the contribution to society and financial cost of care

Actions

- Introduce payment for caring *per se* for full-time Family Carers
- Link the level of payments to labour market equivalents, not to social assistance
- Examine the relative merits of additional options, including the introduction of some form of pay-related aspect to benefit payments and allowing Carers to receive more than one social welfare payment.
- The model in some countries, such as Norway where Carers may apply for a home help position with their local health authority and carry out their duties in this job in relation to the family member that they care for, should be explored in Ireland.
- Provide for continuity of social insurance contributions during periods of absence from the paid workforce because of caring
- Make home care subvention payments available nationwide
- Harmonise the current mix of supports under the health system and within the tax system, to ensure universal and equitable access for all.
- The possibility of using tax credits to provide income support for Carers should be explored.

An adequate and fair system of payments for Carers must be at the heart of the strategy for Carers in Ireland. The economic contribution of caring work is clear and it must be commensurately recompensed. This is clearly not the case at present and points to a basic injustice in society.

The Facts

- There is currently no system of payment in Ireland to Family Carers for their work as carers; only basic income support is available for some carers.
- Fewer than one in seven Carers receive one of the income support payments for Carers (Carers Allowance or Carers Benefit). 23,266 Family Carers are in receipt of Carers Allowance while a mere 666 Family Carers receive Carers Benefit. (Ref: appendix 1, page 29), leaving a total of 125,488 Family Carers without any income support at all in Ireland.
- Foster Carers Allowance can be more than double the maximum of Carers Allowance. Ref: Appendix, page 29.
- The rate of payment of Carers Allowance (**€153.60**) and Carers Benefit (**€163.70**) is only about one-third of average net weekly earnings in Ireland. (Ref: appendix 1, page 29)
- Anyone who is solely dependant on a Carer payment for her/his income is living in poverty.
- In addition to loss of income, families often have direct financial outlays to meet the costs of care. These can include additional day-to-day costs (transport, heating, dietary and so on) as well as costs of care services (for example, respite care in the home). There is no coherent approach to supporting families with these costs at present.

On the one hand, the view that employment is the way to eliminate poverty and reduce social exclusion is a core plank of economic and social policy in Ireland, and dual income households are accepted as a necessity to maintain an adequate standard of living for families. On the other hand, families are expected to provide the bulk of care, typically with little or no support and recompense for the losses of paid employment income that can often ensue.

At present there are two main income supports for Carers – Carer’s Allowance and Carer’s Benefit. Carer’s Allowance is a means-tested payment, payable to eligible full-time Carers in the home (a maximum of 10 hours per week of employment or training is allowed). About 23,000 Carers currently avail of this payment. Carer’s Benefit is a social insurance payment, payable to Carers (for a maximum of 15 months) who take leave from work in order to care on a full-time basis.

These payments are currently pitched at a level that represents less than one-third of net average weekly earnings in Ireland. The implications are clear. To begin with, these payments as currently formulated are not in any way intended to recompense Carers for their loss of paid employment income. In addition, anyone who must rely on these payments as their only source of income is at a high risk of poverty. This situation must be redressed as a matter of urgency – the contribution of Carers must be properly recognised and, where income losses occur, these should be recompensed at levels that relate to labour market benchmarks, not basic social assistance.

The situation of Carers who are in paid employment also needs to be addressed, particularly Carers whose caring commitments only allow for part-time working. Such Carers should be compensated for the loss of income that results from reduced hours of work.

There are longer-term, lifetime issues to consider as well. Lengthy absences from the paid workforce can have serious implications for pension entitlements later in life. It is imperative that Carers are not penalised in this way and that social insurance contributions are maintained for all Carers during periods of absence from employment because of caring.

Recently there has been quite a lot of attention to the issue of payments to Carers. One aspect has been the pilot introduction of home care subvention payments to provide families with financial help to purchase home care services privately. Consideration is also being given to the introduction of an integrated benefits package for home care, with the possibility being aired that the current Carers Allowance payment might be subsumed within this.

The move towards a home care subvention grant has some merit because it will help to rectify the current imbalance in favour of supporting residential care costs (through the nursing home subvention scheme). However there still needs to be more consultation as to the breakdown and exact uses of the grant and clarification about how it is to be administered.

The idea of a single, integrated benefit payment for home care needs some further consideration. Some elements within the options that are currently being explored have much merit, for example, the possibility of universal access independent of means and the provision of a mix of

services or cash benefits to meet different needs and circumstances. These aspects should be implemented as soon as possible.

However, the possibility that the Carers Allowance might be subsumed within such a benefits package raises serious questions in relation to the goal of recompensing Carers for loss of earnings because of caring. A comprehensive and fair strategy for Carers must separate support towards the costs of care and income support for Carers. All families with caring commitments should have access to the proposed benefits package. In addition, Carers who suffer loss of earnings must receive separate recompense, at a level that is linked to labour market criteria, not social assistance.

In fact, to meet the diversity of Carer circumstances and needs, a number of options may need to be provided in relation to the provision of financial recompense for Carers.

The possibility to use tax credits to provide income support for Carers should also be explored, both where a Carer must reduce working hours to care and where they must leave the workforce for a period. Both individualised credits and shared credits between couples should be given consideration in this regard. The current Home Carer Tax credit could be a vehicle, but would need to be substantially increased and redefined.

Education and Training for Carers

Objective

To enhance the caring skills required by Carers.

To ensure equality of opportunity and equip them with the additional skills necessary to re-enter the workforce should their caring commitments end.

Actions

- All health authorities should have Carer education and training strategies in place.
- Provide essential supports to ensure that young carers remain at school.
- Extend the existing training in caring skills to ensure that all Carers are able to receive the necessary recognised training.
- Ensure that Carers have equality of access to lifelong learning.
- Specifically target Carers as a group to be encouraged and supported in the take up of return-to-work-training opportunities when their caring responsibilities end.
- Provide Carers with the necessary respite services to enable them to participate in training.
- Ensure that such education and training is accessible to Carers, including the use of new technology, TV and eLearning where appropriate.

The Facts

- Research indicates a substantial demand for education and training among carers (O'Donovan, 1997).
- The Carers Association provides City and Guilds certified Care skills training to over 500 Carers per year.
- Compared to a total of 149,000 Carers, much needs to be done in this area

Recognised education and training for Carers is a crucial requirement. Where Carers have the necessary skills the quality of care will be better, the Carer's caring experience will be more fulfilling and there are likely

to be fewer negative impacts on the Carer's own health and well-being and that of the cared for person.

Depending on the circumstances, a wide range of skills may be needed.

- There is a need for "hands on" skills, for example, dressing and undressing and help with bathing.
- In some instances there is a need for technical skills, where assistive technologies like hoists or other equipment are used by Carers.
- There is typically a need for management skills, to deal with the various health and social services and to generally juggle the competing demands of caring and other aspects of the Carer's life.
- More generally there are a whole series of skills in relation to coping with the caring situation and dealing with the emotional aspects.

A combination of agencies could be used to deliver the actual education and training, including Carer organisations and FÁS. Such training should lead to recognised certification of caring skills. This would help to give recognition to the skilled work of Carers and also provide some documentary evidence that would be helpful in their work careers. Apart from contributing to better quality care in the community, better skills for Carers would also contribute to health and social gain for Carers.

Such education and training needs to be accessible to Carers. This means being provided within easy geographical reach wherever possible and the availability of respite care services that enable Carers to attend courses. In addition, the opportunities provided by the mass media and by new technologies should be exploited, including TV and eLearning.

Lifelong learning is essential in today's world, where occupational profiles and skills change rapidly. Carers are often especially vulnerable in this regard, if they are out of the paid workplace for some time or if their caring commitments make it difficult to find the time to keep skills up to date or to develop new ones.

Particular attention needs to be given to women who have been outside the paid workforce for a long time, perhaps due to child rearing and caring responsibilities. Personal development and back-to-

work courses are needed, as well as more targeted training in particular occupational skills.

The particular needs of young Carers should to be given priority attention. Not only is their school attendance and scholastic achievement at risk, but participation in after-school and other extracurricular activities, which are essential to their social skills acquisition, may be curtailed. These are increasingly important for good educational and life outcomes and it must be ensured that young Carers have equality of access to these opportunities.

Return-to-work and Work-life Balance for Carers

Objective

To give Carers more priority in work-life balance policies and procedures

Actions

- Carry out research to identify the specific work-life balance provisions that are needed to ensure that working arrangements are Carer-friendly
- The Department of Enterprise Trade and Employment, FÁS and voluntary sector organisations should come together to develop work-related training and return to work programmes which also maintain a link with the world of work for Carers who are outside the paid workforce
- Remove unnecessary barriers to Carer participation, for example, the restriction to 10 hours or less of training per week for those in receipt of Carer's Allowance
- Review Carers Benefit so as to make it more flexible allowing Carers to reduce their time in paid employment and provide care. This would be more conducive to real life Caring situations rather than having to take time off in blocks.
- Introduce new legislation to allow for more flexible working arrangements so that people can combine work in the home providing care and work outside the home simultaneously
- Establishment of positive links between unions, employer's representative groups and carers group to facilitate a sharing of information and needs in this area.

The last decade has seen enormous social and economic change in Ireland. We have moved from a time when women tended to leave the workforce to take responsibility for family matters to the current situation where combining family responsibilities and employment outside the home is becoming increasingly the norm for women and, to a lesser extent, for men.

Women Carers are much more likely to be combining caring with working outside the home than previously and are more likely to be working part time than non Carers.

The Facts

More than half of Irish Carers also work outside the home

- The Census of 2002 found that more than half of Irish Carers were also working outside the home
- Many Carers who work outside the home (almost 40% of all women Carers and 11% of all men Carers) work part-time

Although things have changed a lot there still are many carers who are not working outside the home but who would like to if the circumstances were more conducive. In particular, nearly half of all women Carers of working age are not currently in paid employment. There is a need to put in place supports that can ensure equality of opportunity to participate in gainful employment outside the home for all Carers who desire this. Opportunities for access to training and skill development and for appropriate re-introduction to the world of work are needed. More practically, help with caring responsibilities is needed, including greater and more flexible access to home care services and to day care in the community.

Carers who are in the workforce also need supports. For those who wish to continue combining caring and working, and the majority of people with caring responsibilities appear to prefer this, there is a need for greater consideration of Carers needs in work-life balance provisions. Most such provisions at present have been developed with the needs of parents in mind. Some may also be useful for Carers but the requirements of the caring situation, for example, the unpredictability of demands, call for additional measures that are more tailored to the specific needs of Carers.

Some Carers may need to reduce their hours of working in order to be able to manage their caring responsibilities. It is important that their employers afford Carers the opportunity to do this and that income maintenance support is available to offset loss of employment-related income.

Other Carers may need to stop working entirely for a period of time from their paid jobs. The Carers Leave provisions provide a statutory right to take time out and return to one's job later, for Carers who meet the requirements as regards employment and social insurance history. However there is a need for a lot more flexibility in current provisions. For example, many Carers might prefer to opt for part-time working or to take their leave in more flexible ways than having to opt for fixed blocks of time.

Access to up-to-date and accurate Information

Objective

To develop a high class information service for Carers with easy access therefore reducing the stress and strain that is often placed on Carers when trying to access information around entitlements and rights

Actions

- Provide resources to enhance the existing Care Line services to a 12 hour/day service to include an out reach link to other providers
- Develop a dedicated information website for Family Carers (similar to the UK model)
- Strategically extend the existing network of drop-in centres for Carers to include outreach services and hard to reach geographic areas
- There may be scope to broaden the role of some social welfare officials when carrying out assessments with Carers to disseminate information on other services available to them
- Citizens Information Centres throughout the country should be resourced to identify and proactively disseminate information on the rights and entitlements of carers and home care recipients and to assist them in accessing appropriate services.

Carers need information if they are to effectively carry out their caring role and to look after their own needs as Carers.

The Facts

Research shows the importance of information for Carers

- Irish studies have found that access to appropriate information services is a core need of Carers (Ruddle et al, 2002; O'Shea and Hughes, 1994).

The information needs of Carers span a very wide spectrum. They need information about the caring role, what it involves and how it may change over time. They also need information on what services and supports are available, where they can be found, and who can avail of them. Such information must be available at the right time, as and when it is needed. Caring responsibilities can arise very suddenly and Carers need information and support in making decisions that often must be taken very quickly. Apart from information about caring in itself, Carers may also have other concerns, for example about rights of residence in the family home or issues relating to asset inheritance.

All available channels should be used to ensure that information is available and accessible to Carers whenever and wherever they need it. Drop-in centres have an important role to play, because they can provide a broad range of information and support, delivered with a human touch and act as one stop shop for all information on all relevant providers and prevent Carers from wasting valuable time having to piece together information from many different sources. The existing centres provided by voluntary organisations need to be extended, with support for additional facilities and a wider geographical distribution of centres

The Care Line phone-based service also plays a key role because it can be easily accessed from anywhere, but it needs to be extended to provide 12/7 coverage. Information and support needs can arise at any time of the day or night.

The Internet also provides good opportunities and the Census of 2002 found that 60,000 Carers lived in households with a PC and Internet connection. In the UK, there is an official national web site for Carers, offering a wide range of information as well as additional facilities such as chat rooms for Carers to discuss and share experiences. This is an approach that could usefully be pursued in Ireland as well.

Active out-reach is also needed to ensure that as many Carers as possible are reached. Many Carers are shouldering their burdens without any support or contact with Carer support services. There is a need to put in place a process of systematically identifying Carers and providing them with information, as well as referring them on to appropriate services where necessary.

Apart from addressing the needs of Carers themselves it is also important to provide information and raise awareness more widely about Carers and caring. There is a need for information campaigns to highlight the importance of caring and encourage everyone to play whatever part they can. Employers also need to be targeted to encourage recognition of the needs of Carers and inclusion of their concerns in work-life balance provisions.

References

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APPENDIX 1

CENSUS OF POPULATION RESULTS 2002

Number of Family Carers	148,754
Number of Family Carers providing 43 hours or more	40,526
Number of part time Family Carers	108,228

THE FACTS ON CARERS ALLOWANCE AND CARERS BENEFIT

Carers Allowance (Full Amount) = €153.60

Conditions	Numbers in receipt	
Means Tested , with income disregard set at €540 (couple) €270 (single person)	No. in receipt of Carers Allowance	23,266
	No. in receipt of full allowance	21,089
	No. in receipt of reduced allowance	2,177
	Total No. caring for 2 people	2,993

Carers Benefit = €163.70

Conditions	Numbers in receipt
Must have 39 P.R.S.I contributions in 12 months previous to application. Must have a total of 156 P.R.S.I contributions since entry into employment. Maximum duration of Carers Benefit is 15 months.	666

COMPARISONS

Foster Care Allowance

Providing Care to a child in the following age groups	Amount Per Week
Under 12	€297
Over 12	€324

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