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### **FOREWORD**

'What carers do should be properly recognised and properly supported' Tony Blair, Caring about Carers, A National Strategy for Carers, 1999.

There is a growing recognition across all agencies of the substantial contribution made by informal carers in our communities. There is a desire that this should continue with an equal commitment to work in partnership with carers. We need to make sure that carers receive the support and services that they need and that these are a high quality, allowing them to continue caring. Services must be flexible and able to meet a wide range of carers' needs even when the caring role ends. The National Carers' Strategy states that what carers want is:

- well-being of the person being cared for,
- freedom to have a life of their own,
- maintaining their own health,
- confidence in services,
- a say in service provision.

It is estimated that carers save health and social services £3.6 billion every year in Wales. In Carmarthenshire this equates to £240 million every year. Carers must be recognised as partners in the delivery of services to vulnerable, sick or disabled people in our communities and be respected for their contribution.

Before writing this document we asked carers to tell us about their concerns. Carers have many concerns that are sometimes similar and sometimes very different, depending on their individual circumstances. With so many different needs identified it has been difficult to plan for them all. The strategic action plan recognises where we are and sets out to build a foundation that recognises carers and gives them the information and support they need. Following this, carers services developed in the future will have a solid base from which to grow. In addition, the action plan has recognised that carers' breaks – holidays from caring - are the priority for carers, particularly carers' needs for security and care for their charge in an emergency.

The three-year span of the strategy will see carers recognised as an important part of social and health care in Carmarthenshire and valued for their commitment despite the loss of opportunity and lifestyle that being a carer can involve. With the support of elected members, senior officers and carers for this action plan, along with a practical and determined approach from all concerned, we will achieve the goals we have set. Whilst doing this we will be looking ahead and planning future services with greater confidence.

County Councillor Kevin Madge

Kein Madge

**Executive Board Member Health and Social Care** 

**Carmarthenshire Carers Champion** 

**Ken Jones** 

**Chair of Carmarthenshire Local Health** 

### CARMARTHENSHIRE CARERS STRATEGY WORKING GROUP

### **BACKGROUND**

### A Working Definition

A carer is a person who has taken responsibility for the care of a dependent individual, who is sick, disabled or vulnerable, on an unpaid, regular basis. A carer may be a husband, wife, partner, relative, neighbour or friend. Carers do not necessarily live in the same household as the person for whom they care.

A carer may also be a young person under the age of 18. In this case, the person receiving care is often a parent, but can be a brother or sister, grandparent or other relative who needs support. Young carers are "children in need".

### **Carer Contribution**

Very few people needing health and social care rely on formal services alone which highlights the role that informal carers provide. Caring may mean medical care such as: changing colostomy bags, technical interventions and wound management; administering or supervising medications to ensure compliance; providing or encouraging therapy regimes, or to improve and maintain functioning.

It can also involve providing a supportive environment that minimises risk, such as assisting movement and walking to prevent falls, encouraging and modifying cooking and eating habits to fulfil changed dietary needs, and supervising service users who are confused or challenging.

Such assistance may involve dealing and living with the depression, frustration, anxiety or denial that accompany the illness itself or the changes in lifestyle required by the service user. The carer role, in addressing the psychological or emotional components of self-care and recovery, is particularly challenging for carers but largely invisible.

Health care also involves arranging and going with service users to medical and allied health appointments, and being aware of changes in the person's health that may require attention from the doctor, nurse or hospital treating them or from which they have recently come home.

Central to the service users' ongoing health and well-being is the contribution family carers make to their personal care – providing or supervising such activities as bathing, eating, grooming and dressing – to maintain hygiene, comfort and diet. Household activities such as laundry, cleaning, shopping and managing money also support these goals.

Carers are undoubtedly part of the health care team, but are hardly ever recognised for it despite the £3.6 billion their care of people equals every year in Wales (the same as the NHS budget in Wales).

## **Impacts of Caring**

Compared to paid members of the team, carers have very stressful working conditions. They have little choice, no background education, no shifts or paid annual leave, limited information and training in care provision, no occupational safety checks or line management support, not to mention adequate remuneration! Under such conditions, health and social care staff would not accept care responsibility (Arksey et al 1998).

Providing high levels of care can place great stress upon carers, especially where they have other life commitments or are themselves ageing. Caring can affect the carer's relationship with and care of other family members, and lead to social isolation as friendships and interests become curtailed. Some are forced to leave or cut back on work or studies (sometimes forfeiting the opportunity to gain a pension), and many may experience financial hardship, associated with reduced income and greater expenses.

Caring tasks and ongoing stress can significantly harm carers' health (Briggs & Fisher 2000) including injury, exacerbation of existing health problems, lowered immunity and poor mental health (anxiety, depression, grief and stress). A growing body of evidence (Guia 2003) indicates that such stress can irreversibly place at risk the carer's own health (e.g. cardiovascular disease, skeleto-muscular problems). Without intervention, this in turn increases the carer's use of health services and makes it more difficult to care for the service user in the community.

# From Carers National Association figures and the 2001 Census, it is known that there are:

- 22, 000 carers in Carmarthenshire
- 12,861 of whom provide up to 20 hours of care per week
- 2,729 provide care for between 20 and 49 hours per week
- 6,250 provide care for more than 50 hours per week
- 500 young carers in the county

### Legislation clearly lays down a statutory responsibility to meet carers' needs:

- Chronically Sick and Disabled Persons Act 1970
- Disabled Persons Act 1986
- Children Act 1989
- NHS and Community Care Act 1990
- Carers (Recognition and Services) Act 1995
- Carers and Disabled Children Act 2000
- Carers (Equal Opportunities) Act 2004

# This responsibility is reinforced by a number of key guidance documents:

- Caring about Carers A National Strategy for Carers, 1999
- Caring about Carers A Strategy for Carers in Wales, 2000
- Social Services: Building for the Future A White Paper for Wales, 1999
- Better Health, Better Wales 1998
- Tackling Substance Misuse in Wales A Partnership Approach, 2000

In response to these prompts agencies in Carmarthenshire have considered the issues for carers through key corporate and multi-agency documents, namely:

- Thinking Together, Planning Together, Doing Together-Carmarthenshire Community Strategy
- Feeling Fine: A Health, Social Care and Well-being Strategy for Carmarthenshire
- Children and Young People's Framework Plan.

Development of this action plan has been informed by the *Strategy Discussion Document* (2001).

### **Carer Consultation**

Carers' views have been sought in a number of ways. Approximately 650 people were sent a questionnaire through various agencies and mailing lists and 141 replied. The same questionnaire was circulated through the County Council e-mail system and eight responses were received. Carers' Week and Carers' Rights Day have enabled staff to consult with carers informally on several occasions.

Sub-groups were formed to analyse the response to the questionnaire, map needs and identify the key issues to be taken forward within the strategy. These covered:

- Young Carers
- Breaks for Carers
- Carers' Health
- Carers' Assessment

### **Summary of needs assessment**

There are nearly 22,000 unpaid carers in Carmarthenshire (Census 2001), a figure that represents 12.5% of the population. The Amman Valley, Gwendraeth Valley and Llanelli have the highest proportion of people involved in informal caring. Carers are disadvantaged in many ways:

- National studies report that 51% of carers have suffered a physical injury since they began to care and 52% have been treated for a stress related illness.
- Long-term carers, in particular, can suffer financial hardship giving up paid employment, unable to save for a pension, surviving on benefits.
- Half of all carers' incomes are within the lowest two-fifths of income distribution.
- Carers have to bear additional costs of caring such as higher transport expenses and specialist dietary needs. They often pay for extra heating, equipment and short break care.
- One in four carers provides care for between five and ten years.
- 6,250 carers in Carmarthenshire provide more than 50 hours of care every week (many of these are caring 24 hours a day, seven days a week).
- Many carers commit themselves to a lifetime of caring.
- Carers are socially excluded.
- Carers do not receive adequate support or training.
- Carers are entitled to a life of their own both during and after their caring role.
- Carers have rights to which they are entitled.

- Young carers are children in need.
- Recognising carers as a resource is vital. Protecting resources must be a basic requirement to maintain services that provide health and social care.

Carers consultation in Carmarthenshire has identified the following needs:

- Support for carers (emotional, advocacy).
- Identifying and recognising carers.
- Better health for carers.
- Comprehensive information in a variety of formats.
- Improved carers' assessment activity.
- Improved assistance with personal care and mobility of the cared for person.
- A variety of flexible short breaks.
- The specific needs of young carers.
- Support for employees who have a caring role.
- Opportunities for carers to return to work or education.
- Opportunities to maintain leisure and social activities.
- Contributing to the planning of services.
- Improved transport services.

### **ABOUT THIS STRATEGY**

This strategic action plan will attempt to create the necessary framework to support carers in Carmarthenshire in the long-term. It will, during its implementation, also look to the next steps required to deliver more and better carers' services.

The document does not set out to tackle in the short-term all of the carers' problems of which we are aware. Knowing about a problem or need is the first step in working towards solutions, but reaching these solutions will depend on the level of capacity and resources available to us. The strategy is intended to be realistic and deliverable. We are embarking on a journey that has "A better lifestyle for carers" as its destination. The intention of this initial action plan is to give us a roadworthy vehicle in which to travel.

### CONSULTATION

The draft version of this strategy was widely circulated to individuals and organisations during the summer of 2005. Over 100 responses were received to this consultation. Most respondents had a good overall impression of the document and thought it was easy to read. The comments made have been used to improve the final document by simplifying the language and including a glossary of abbreviations. A majority of people responding also thought the strategy was comprehensive and that the emphasis in it was right. The actions in the strategy have been expanded to reflect the points made by carers. A more detailed summary of the responses is provided in Appendix 2.

### A VISION FOR THE FUTURE

The development of this strategy has identified many needs of carers that reflect the extent and diversity of the different roles that carers undertake. Services for carers in the future will be underpinned by the following principles:

- Recognition that carers are individuals with their own expertise, skills and needs.
- Choice should be given to take on and/or continue the role of carer and the degree or level of care provided.
- Partnership at all levels of policy making, service planning and reviews which affect carers, acknowledging that a carer's time is limited by the role they fulfil.
- Equity of access to support and services, regardless of post code, gender, ethnic origin, culture, age, disability, religious beliefs, linguistic background or sexual orientation and whatever the illness or disability of the person for whom they are caring.
- Being informed with a range of appropriate information that is accurate, honest, and accessible.
- **Financial security** through information on available benefits and the monitoring of care charges.
- Co-ordinated and quality services all agencies should work together to provide efficient, effective, needs-led and flexible services for carers.
- **Inclusion** of carers in all services, so that personal circumstances are not disadvantaged by the way that agencies provide their services.
- Recognise children as children first.

Putting these principles in place on behalf of carers throughout the health and social care sectors will enable new and different services to emerge from the process of ongoing consultation, planning and service monitoring. Carers will be included and supported to

participate in all of these activities, making sure of their recognition as full partners in the delivery of care within our communities.

### **INTRODUCTION**

The publication of this strategy has been delayed due to the Partnership's commitment to deliver the actions herein. Resources to ensure we can do what we say we intend to do have taken a while to identify and secure. However we can now move forward confidently. Many aspects of the strategic actions have begun where resources have not been a barrier. These include: carers assessment and awareness training, carers emergency cards, developing carers support workers with the voluntary sector, carers assessment included in Unified Assessment Process and carers information boards for hospitals.

Our strategic intent has been based on the national policy framework, the information currently available and what carers have told us. We recognise the need to extend our work with carers so that we can show that our plans and what we hope for represent the majority of carers in Carmarthenshire in order to deliver fair services.

Regular and substantial carers have the right to be offered an assessment of their needs. An improving level of assessment work with carers is evident and we need to build on this in order to demonstrate our commitment to carers. Carer awareness and assessment training over the course of this first strategy will strengthen our intention to give carers the attention they deserve and to recognise their contribution and their health and well-being.

To understand what carers need we have to try and contact as many carers as we can. Carers, throughout all service areas where they can be identified and especially in communities and hospitals must be recognised for the part they play in helping us to deliver care. Being accepted as equal partners in care teams will help make this happen. Carers provide the cornerstone of community care by being there to support people all of the time and making sure that they can live as independently as possible. Young carers below the age of 18 years are "children in need" and will be regarded as children first. Schools and youth services must play their part in identifying young carers and making sure that they get the help they need and do not miss out on their education or any part of growing up.

Having a break from caring is really important to carers as stated by 97% of respondents to the Carmarthenshire survey. A variety of short breaks services do exist in the county across service areas that include health and social care and the voluntary/independent sectors. However, the demand far outstrips the availability and a recent national survey (10% of respondents were from Carmarthenshire) has highlighted that 50% of carers will not accept the short break service available because of its nature and quality (Wales Carers Alliance 2004). By seeking out hidden carers and providing good quality assessment we shall form a clear picture of carers' short break needs so that planning new services to meet those needs will be better informed.

Carers' health needs are very important, especially whilst they are caring. Depression and back injuries are more common amongst carers than the rest of the population whilst there are many carers who are suffering sickness or disability that is nothing to do with their caring role. Family doctors and the people who work in surgeries will be targeted to improve services for carers. Other staff in hospitals and the community will be made more aware of carers' health needs.

### 1. IDENTIFYING AND RECOGNISING CARERS

### Aim

Carers will be identified and recognised for their contribution.

## **Objectives**

- Carers are identified from the outset of their caring career.
- Carers feel that their contribution is valued and recognised.
- Carers feel empowered to control their level of commitment and be included as an equal member of the care team.
- Service users' care plans must acknowledge the role of carers.
- Carers will have their own health and well being considered.
- Carers must be involved in the review of care plans.
- Young carers are recognised as children in need.

## The situation at present

- Lack of a co-ordinated and pro-active approach to carers from service providers means the majority of carers are not known.
- Many carers who receive services and support at present are grateful for the help they
  receive but consultation with this group has shown a deficit in several key areas.
- Carers are identified at point of crisis.
- Carers' ability and willingness to provide care are assumed.
- Carers' health and well-being are threatened by their caring role.
- Carers are not routinely involved in the planning and delivery of care.
- Young carers are a hidden group.

No specific funding is directed at identifying and recognising hidden carers.

# 1. IDENTIFYING AND RECOGNISING CARERS (TO INCLUDE YOUNG CARERS) – ACTION PLAN

AC	CTION	Who will do this?	By when?	<b>Cost</b> (2006–09)	Outcome
1.1	Specially targeted publicity campaign aimed at helping people to recognise themselves as carers.  Continue promoting Carers Week and Carers Rights' Day.	DPPC/LHB/ JCDO Carers project. Carers Alliance. Primary Care. Secondary Care. Others.	Year 1 and ongoing	£500 LHB/LA managed through CCP. £9,000 Total (£3,000 per year)	People recognise themselves as carers and access advice on how to get support and find out about their rights in the first instance.  Continued outreach to hidden carers and informing on carers rights.
1.2	Awareness raising and training for all primary and secondary care teams is inclusive of Unified Assessment Training, Person Centred Planning and the Care Programme Approach as they relate to carers.	JCDO Primary Care Secondary Care	Year 1 and ongoing as necessary	Role inclusive	More carers will be identified and their contribution recognised. Carers' health, carers' information and carers' rights' will be maintained.
1.3	Carers' assessment/awareness and recognition training for appropriate health and social care staff that reflects carers in relation to Unified Assessment Process, Person Centred Planning and the Care Programme Approach.  Introduce carers to the training forum and provide subsistence, travel and replacement care.	JCDO SCH Training Section NHS Trust Training Depts.	Year 1 and ongoing as necessary	Existing training budget.  £6,000 total (£2,000 per year)	Carers' rights are upheld. Carers' issues are embedded in professional practice. Carers are identified and recognised in service user care plans for their contribution. Carers' needs are known. Carers' health maintained.  Carers are involved in training.

AC	CTION	Who will do this?	By when?	Cost (2006–09)	Outcome
1.4	Produce an aide memoire for all relevant staff that outlines carers' rights and local carers' services contacts.	JCDO Information Officer CCC	Year 1 and ongoing updates	£300 per year (£900 Total)	Workers have information on carers' rights and services in a 'handy' format.
1.5	Promote young carers and their specific needs to partner agencies best placed to identify them by securing training and awareness raising opportunities.	Young Carers' Project Children's Services & Lifelong Learning Dept.	Year 1 and ongoing	£3000 per year managed through YCP (Total £9K)	Staff in education and youth services will take a more proactive approach to identifying young carers. Young carers are recognised as children in need.
1.6	Campaign for the inclusion of young carers by mainstream younger people's services.	Education & Children's Services; Children's JCO JCDO	Year 1 and ongoing	Role inclusive	Young carers and sibling carers are included in young people's services.
1.7	Establish a working group to plan more services for young carers. Establish a 'Friends of Young Carers' group within Carmarthenshire.	JCDO JCOCS YCP MARG	Year 1	Included in <b>1.5</b> above	Potential for additional resources for additional services.

AC	TION	Who will do this?	By when?	Cost (2006–09)	Outcome
1.8	Develop and agree standards of practice and local performance indicators within all carer related service areas and monitor through performance management frameworks.  Identify responsible officers.	JCDO Social Care Primary Care Secondary Care	Year 3	Role inclusive	Continuous improvement.
1.9	Secure a Carers' Strategy Implementation and Commissioning group to oversee the work of the strategy and to act as the planning and consultation group for all strategic development in the county with an impact on carers.	CCP JCDO CA JCT MARG	Year 1	Included in <b>1.3</b> above	Carers maintain a high profile across all relevant planning groups. Carers issues are considered and planned for in all relevant service developments.
	Identify Carers' Champions within all Service area planning groups.	MARG	Year 1		All service planning groups have continuous carer representation.
1.10	Create a referral pathway from Primary Care and Secondary Care to Social Services.	JCDO DP & PC LHB & PC staff	Year 1	Nil	Carers are referred to Social Services (or delegated others) for assessment.
1.11	Agree policy between Adults and Children's Services to allow young Carers a seamless service through Transition.	MARG SPO Adults SPO Children	Year 1	Nil	Young carers becoming adults will have a consistent level of support.

### 2. INFORMATION FOR CARERS

### Aim

From the outset carers will have information that tells them what they need to know.

## **Objectives**

- Health and social care workers have a good range of information to give to carers.
- Provide a range of information to carers that is:
  - Clear:
  - User friendly;
  - Up-to-date:
  - Accessible:
  - Age appropriate;
  - In their preferred language;
  - In a range of formats/media including the Internet and telephone to signpost them to additional support and services.
- Information for carers will include:
  - Their rights as carers;
  - How to get an assessment of their needs;
  - Services and support available to carers locally and county-wide from all services and agencies;
  - Services and support available to carers nationally;
  - How to access support and services;
  - The illness/disability/condition of the person they care for;
  - The cost for services where they apply;
  - What to do when things go wrong;
  - How to make a complaint.

# The situation at present

### **Carmarthenshire Carers' Project:**

- Carers' Packs (containing general information and a useful directory of contacts);
- Quarterly Newsletter:
- Carers' Rights Day;
- Carers' Week;
- Telephone signposting.

Not enough money to meet growing demand for carers' packs, newsletter and events.

Source of funding	Frequency	Amount
Local Authority	Annually	£24,000
Local Health Board	Annually	£6,000
Total	Annually	£30,000

# **Carmarthenshire Young Carers' Project:**

- Based with Barnardos in Llanelli;
- Serves young carers who have been assessed as needing a service to make sure that their educational, emotional and developmental needs are met;
- Provides a link to other services;
- Provides advice and information.

Well established but inadequately resourced and over subscribed.

Source of funding	Frequency	Amount
Local Authority – Core Funding	Annually	£18,250
Local Authority – Carers' Grant	Annually	£33,000
Local Health Board	Annually	£17,300
Barnardos	Annually	£20,000
Total	Annually	£88,550

# **Llandovery Carers' Support Worker Project:**

- GP based dedicated carers' support worker;
- Identifying carers and creating a database of carers;
- Signposting to services;
- Giving information:
- Providing low level emotional support.

Source of funding	Frequency	Amount
Local Health Board	Annually	£27,000
Local Authority – Carers' Grant	One-off	£4,000
Total	Annually	£27,000

### **Stroke Association:**

- Dedicated family/carers support worker;
- Specific information;
- Specific advice and signposting.

Established and well-used service.

Source of funding	Frequency	Amount
Local Authority – Carers Grant	Annually	£31,348
Total	Annually	£31,348

## Mencap:

- Family Advisory Service Children;
- Family Advisory Service Adults;
- Newsletter:
- Information, advice and signposting.
- Valued by parent carers.

Source of funding	Frequency	Amount
Local Authority – Core funding	Annually	£48,000
Local Authority – Carers Grant	Annually	£15,711
Total	Annually	£63,711

# **Carmarthenshire County Council:**

- "Are you a carer?" leaflet;
- Wide range of other information about disabilities;
- County Council website;
- Social work teams offering information and advice.

Source of funding	Frequency	Amount
Local Authority	Annually	Varies
Total	Annually	Varies

## **Carers Wales:**

- Variety of information;
- Variety of formats.

General information – does not have a local focus.

Source of funding	Frequency	Amount
Carers Wales	Varies	Varies
Total	Varies	Unknown

# **Alzheimer's Society**

- Information for carers:
- Advice for carers;
- Signposting for carers.

One part-time worker who is based in Prince Philip Hospital.

Source of funding	Frequency	Amount
Local Authority – Carers Grant	Annually	£6,000
Alzheimer's Society	Annually	Varies
Total	Annually	£6,000

### Others:

- A variety of information exists within all agencies but it is mostly aimed at service users.
- There is a clear need for an audit of existing information to establish a baseline.

# 2. INFORMATION FOR CARERS – ACTION PLAN

AC	CTION	Who will do this?	By when?	<b>Cost</b> (2006–09)	Outcome
2.1	Audit of all information that is currently available for carers in Carmarthenshire.	JCDO CCP Carer Organisations. LA & NHS Trust staff.	Year 1	£13K per year To introduce admin support to CCP (this support will assist all elements of action plan)	Baseline established. Gaps in the range and type of information will be made known to all concerned.
2.2	Develop joint working with service providers and carers to produce the information required, as identified by audit.	JCDO CCP CCC NHS Trusts Carers' Organisations. Carers.	Year 2 and on-going	Costs met from existing budgets where possible. Ongoing identification of resources as appropriate.	A comprehensive range and type of information for carers will be available across service areas.  Carers will be better informed on their rights, specific clinical issues, how to access services, the cost of services (where they exist), how to get support and advice and how to make a complaint.
2.3.	Performance manage the quality and availability of information.	Service providers Carers JCDO	Year 2 and ongoing	Role inclusive	Continuous improvement.

# 3. BREAKS FOR CARERS

#### Aim

Carers should have the opportunity for regular breaks suited to their individual situation and their need to spend quality time doing something other than caring.

## **Objectives**

- Crisis services will be made available to respond rapidly to meet the needs of carers and those for whom they care.
- Carers' needs will be taken into account when service user care pathways are being planned.
- Improve the short break provision presently available in terms of quality, diversity, flexibility and accessibility.
- Develop a central register or bureau of short breaks care in Carmarthenshire.
- Develop more opportunities for breaks where support is offered within the individual's home.
- Charging policy for carers must be clearly explained and charging minimised where possible.

## The situation at present

# Former Carers' Grant - £399,085 (Now transferred into the Revenue Support Grant)

The Carers' Grant supports carer organisations to provide services for carers. The national strategy "Caring about Carers" identified breaks for carers as a priority and monies from the grant must be used for this provision in the main. Approximately two thirds of this money provides a variety of breaks for carers (either directly or indirectly).

### Children's Services

Short-break provision for children with disabilities is varied, ranging from residential care to fostering/shared care and domiciliary care. Social Services provide funding and services.

### **Adult Services**

Short-break provision for adults is similarly mixed but is known to be lacking, for example, residential short-break care provision for older adults experiencing dementia or adults experiencing severe mental illness.

Development of new services is underway, for example, the Adult Placement Scheme and several key strategies such as the Strategy for the Care of Older People and the Joint Commissioning Strategy for People with Learning Disabilities are planning to review provision.

### **Comments**

Carers need to have time for themselves, to maintain their physical and mental health, to have more quality time with the person for whom they are caring, to have more time with other members of the family and friends or to pursue other interests.

Carers should have their views fully considered in determining how breaks should be provided. If the short break offered is not suitable then the anxiety and disturbance caused take away the value of the break for the carer.

In the carer questionnaire survey 97% identified the need for breaks. However, responses clearly indicated that carers wanted access to a range of different types of breaks rather than more of a single type.

Knowledge of short breaks and the availability of short breaks is not something that all known carers are aware of. Carers receiving respite breaks can have them regularly but, in the main, there are not enough short breaks available. Access to short breaks is unfair at present and this needs to be addressed. A detailed register of short breaks that is maintained from a central point and promoted to carers would, in the first instance, help carers and professionals to access short breaks and will inform ongoing needs analysis.

Reaching out to hidden carers will help develop a better picture of the need for short breaks services. New or different services will be developed as monies become available. The Carers (Equal Opportunities) Act 2004 says that social services departments have to consider carers' needs for employment, training, education and leisure when carrying out an assessment. This will increase the pressure on service providers. Getting to a position that tells us what type of short breaks are required and how many are needed has to be the most important goal because it is this that will help us to shape services for carers in the future.

We will need to develop and have ready suitable bids to try and access any new monies that become available. The action plan sets out to address the need for service providers, statutory and voluntary, to work together and have business plans in place that can be changed or shaped for submission to funding bodies. Getting as much money as possible from outside sources has to become a priority because missed opportunities mean fewer short breaks for carers and bigger burdens for the authorities. The action plan will also describe how carers, ex-carers or members of the public will be sought to take up roles of responsibility. If suitable candidates for these roles can be found from within our communities the potential to access external funding will be greatly improved.

# 3. BREAKS FOR CARERS - ACTION PLAN

AC	CTION	Who will do this?	By when?	<b>Cost</b> (2006–09)	Outcome
3.1	Develop a countywide register of respite provision.	JCDO CCP Voluntary sector providers Statutory sector providers Private/independent providers	Year 2	Role inclusive (CCP admin support as in 2 above)	Type, availability and criteria for short breaks will be known along with costs where appropriate.  Increased number of carer assessments (1 above) will demonstrate levels and type of short break provisions that are required.  Better informed planning.
3.2	Work with the Joint Commissioning Team to ensure strategic development across all service areas considers short breaks provision for carers.	JCDO Joint Commissioning team	On going	Role inclusive	A greater variety of short breaks is available and available more frequently.
3.3	Multi Agency Reference Group will work in partnership with carers to develop new types of short break services that fit carers' wishes.	MARG JCDO Carers Organisations Voluntary groups	Year 1–3 and on going	New funding sources to be sought.  De-commissioning and re-commissioning existing services.	Carers contribute to the review and planning of new or different short breaks services.  Business plans will be in place and available to support funding bids and service development.

AC <sup>-</sup>	TION	Who will do this?	By when?	<b>Cost</b> (2006–09)	Outcome
3.4.1	Campaign to recruit volunteers who are wiling and able to take on responsible roles within carers groups that will attempt to access additional monies from outside sources.  Develop partnerships with Regeneration department and Communities First initiatives to assist.	JCDO CAVS Carers Alliance Carers CCC External Funding Office	On Going	Funding to be applied for	External funding becomes accessible.  Potential for new and additional services.
3.5	Include emergency replacement care plans in all service users' community care plans where there is a regular and substantial carer involved.	All service managers JCDO Commissioning team Carers' organisations	Year 1	Commitment from community care budget	Carers can access emergency replacement care. Carers feel confident they will receive replacement care in emergencies.
3.6	Distribute 'I am a carer' emergency cards to all carers receiving carer's assessment.	JCDO CCP Carers Alliance	Year 1 and ongoing	£500 per 10,000 cards	Carers will feel less stressed about leaving the person for whom they care for any length of time.

## 4. COMMUNITY SUPPORT WORKERS FOR CARERS

### Aim

To provide a range of support for carers that reduces the amount of stress they suffer and helps them to maintain their caring role.

# **Objectives**

- Establish carers support workers linked to GP practices.
- Provide a link for carers to initial assessment and additional or other services.
- To give carers information.
- Provide low-level emotional support for carers who are distressed.
- Provide someone to speak up for carers.
- Provide support for community teams and primary care teams.
- Develop self-help groups for carers in communities.
- Help carers to take part in the review and planning of services.
- Find out about carers' training needs.

# The situation at present

Services providing support and information to carers
Carmarthenshire Carers Project
Young Carers Project
Stroke Association
Mencap
Llandovery Carers Support Project
Alzheimer's Society
Carmarthenshire County Council Substance Misuse Team
Hafal

There is a description of these services in the previous chapter – Information for carers

- Carer support is limited. Carmarthenshire Carers Project has one worker who
  has no secretarial support and no time to work directly with carers.
- Young carers with severe needs receive help to overcome them. Young carers with lower levels of need receive no services at present.
- Stroke patients' families receive a service from the Family Support Worker.
- Families of children and adults with learning disabilities receive an advisory service.
- Carers in Llandovery and Llandeilo receive a support service.
- Carers of elderly people with a dementia type illness receive support from 2 part-time workers with the Alzheimer's Society in the Llanelli, Dinefwr and Carmarthen areas.
- A new substance misuse family and carer support worker has just been employed by Carmarthenshire County Council.
- Hafal host a Carers' Advocacy and Support Worker for mental health carers.

# 4. COMMUNITY SUPPORT FOR CARERS – ACTION PLAN

ACTION	Who will do this?	By when?	<b>Cost</b> (2006–09)	Outcome
4.1 Develop disability based carers support worker posts that will have strong links with doctors' surgeries in the community and in the hospitals (this initiative will be a partnership between all local stakeholders, especially the voluntary sector).	MARG JCDO CCP LHB LA CAVS/Vol Sector	This will depend on the availability of funds.	See appendix 1	Carers in Carmarthenshire benefit from:  Support from the onset of caring  Emotional support/counselling  Signposting and information  Advocacy  Accessing assessment, services and equipment  Maintaining their health  Training  Having a say in planning  Support to establish local carers' groups  Primary care, secondary care and social services teams benefit from:  Carers' contact  Specialist workers to refer to.

### 5. OPPORTUNITIES FOR CARERS

### Aim

Carers continue to have a life of their own.

# **Objectives**

- Carers feel confident to make informed choices.
- All agencies work together to uphold the rights of carers.
- Employers throughout the county are aware of and adopt carer friendly work policies.
- Carers are helped to remain in work or to return to work.
- Education and leisure services develop carer friendly courses and activities.
- Carers are included in social inclusion policies (to include younger people's services and rural transport services).
- Carers are confident of the services that support them.
- Carers are supported at the end of their caring role.

## The situation at present

Carer identification and recognition are basic targets of this action plan and will be the beginning of improving how we provide services and promote carers' issues within our communities. At the moment the way we do this is not reliably the same for everyone. In some areas there are examples of good work and in other areas there are examples of poor work or no work at all to benefit carers. The current legislation puts a duty on Local Authorities to provide regular and substantial carers with an assessment of their needs (Carers and Disabled Children Act 2000) whilst the Carers (Equal Opportunities) Act 2004 imposes a duty on the local authority and its partners in the health service to tell carers of their right to assessment and where possible the provision of services. Social services will need to amend procedures to ensure that eligible carers are routinely offered an assessment and that assessments take into account education, work, training and leisure needs (LGIU 2004).

### Comment

Many of the objectives mentioned above will be met through action plans 1–4, identifying, informing and supporting carers will all contribute to better recognition and services for carers. The following action plan will look at the need to develop more work, education and leisure opportunities for carers that reflect a positive, broad approach and one that considers carers whose caring career has ended. Replacement care is vital to helping carers to have a life of their own and a huge increase in the need for money to support this is required. This plan recognises that need but does not address it due to the present demand and pressure on all budgets. Work to access new monies and to identify where present monies can be reallocated will be ongoing.

# 5. OPPORTUNITIES FOR CARERS – ACTION PLAN

ACTION	Who will do this?	By when?	<b>Cost</b> (2006–09)	Outcome	
5.1 Reconvene the Action for Carers and Employment (ACE) group (disbanded in 2004).	Representatives from MARG	Year 1	£6000 over 3 years	Implementation of the Carers (Equal Opportunities) Act 2004.	
ACE will work with MARG to look at the employment, training and leisure needs of carers in	All previous members			Carers are represented at policy and service development level.	
Carmarthenshire and develop/advise on	Carers			More opportunities for Carers.	
service/policy development				Further information to support the replacement care/respite needs analysis.	
<b>5.2</b> Promote carer friendly work policies within the Health, Social Care and Well-being Partnership organisations. Develop models of good practice.	JCDO ACE	Year 1	Unknown Resources to	Statutory services have carer friendly work policies.	
organisations. Develop models of good practice.	Human Resource Departments of LA, LHB, Trusts,		meet new costs will	Employers become more aware of carers' needs.	
Promote examples of good practice to all			have to be identified	Carers are helped to remain in work.	
employers in the county.				Carers are helped to return to work.	
	Employers			Carers maintain a better life balance.	
<b>5.3 MARG</b> becomes a consultative group for all planning forums affecting carers, eg. regeneration,	MARG ACE	Ongoing	Included in 5.1 above	Everybody thinks about carers when planning services.	
workforce, social inclusion, community education, further education, leisure, rural transport.  Part agei	Partner agencies			More organisations and departments become informed of carers' issues.	
	Carers			Carers are included.	
				Carers' particular needs are planned for.	

# Appendix 1

## **FUNDING THE STRATEGY**

### **CURRENT LEVELS OF FUNDING DIRECTED AT CARERS**

#### **Assessment**

The process of assessment for carers in their own right can be identified and isolated as 'a carers' service'. There is a requirement to produce this activity as a performance indicator into the personal social services returns in 2007/2008.

Carers' assessments have become more intrinsic to the work of the Adult Services' teams over the last 2 years with at least ten times the number of assessments occurring now than was demonstrated by a snapshot audit of local authorities conducted in 2002. This positive development is largely the result of having a dedicated Carers Development Officer in post to promote carers' awareness and making a small grant available to carers that has assessment as part of its access criteria. Anecdotal evidence suggests that the incentive of a grant is the main driver of carers' assessments and we can, therefore, assume that the activity is mainly linked to grants. A figure for 2005/2006 can be calculated approximately:

Figure 1

Service area	No of assessments	Cost of assessments*
Adult Services	165	£6,600
Children's Services	N/A	N/A

<sup>\*</sup>Based on Spinal Column Point 35 x 3 hours (£40.00) per average assessment, including travel costs.

Children's Services are tasked with the National Assessment Framework for Children in Need and their Families. Because parent carers are recognised within the core assessment document there are fewer dedicated carers' assessments conducted.

The calculation in Figure 1 suggests that our current contribution to the activity of carers' assessments in Adult Services equates to less than one third of a whole time equivalent of a social work practitioner. Given that we know the scope of the work to ensure all carers are aware of their rights and entitlements to assessment and services (carer numbers referred to in the strategy) the current resources targeted are inadequate. In addition we have to consider that there is a 30% turnover of carers annually, meaning that the work of continuing to support carers will require sustainable funding in the long term.

### **Services**

Current practice in the assessment of need and the delivery of services makes it difficult to distinguish between users' and carers' services. This can be illustrated by the learning disabilities social activity centres, which exist largely to provide services, therapies or interventions for service users but also to provide support to carers. The

two are inextricable and the above example is representative of many. If the service is, however accessed via a community care assessment, it is reasonable to assume that it is intended for the recipient of the assessment – the service user. In Adult Services therefore, we can make the distinction in this way. Children's Services are somewhat different because their assessment processes are inclusive of parent carers' needs.

### **Core Funding**

The Local Authority and the Local Health Board jointly fund Carmarthenshire Carers Project, by £27,860 and £6,924 respectively.

The Local Authority with a commitment of £36,000 supports Mencap's Carmarthenshire Family Adviser Service annually.

The Young Carers Project receives £17,746 from the Local Health Board and £18,248 from the Local Authority annually.

Short breaks services are delivered in a variety of ways from the core budget, both in the Local Authority and the Local Health Board. An accurate analysis of this information is currently unachievable due to the variety of service type, duration, location and regularity. However, overall figures are available.

- The Local Health Board is responsible for the short breaks (respite) provision entitlement associated with continuing care status (where a person's needs determine ongoing nursing care). This year the LHB is budgeting £774,00 for this provision; 54 carers and families currently benefit from this with a variety of short breaks ranging from 8 to thirteen weeks per annum and packages that involve care at home. The cost of nursing care provision varies dramatically according to specialist need and some provision can amount to £5,000 per week or more, with the standard nursing home care cost being £424. The Local Authority Adult Services Division provides approximately 1,378 weeks of short break care in its own residential care homes and a further 110 weeks of short break care are purchased from the independent sector. Together these amount to a commitment of £620,000.
- The Local Authority Children's Services Division provides in the region of £750,000 to support short breaks services within its 2 homes for children with learning disabilities, and a further £203,000 that funds Barnardos to provide additional short breaks for the same group. Last year these services provided 2,791 nights of replacement care. The data for analysis of numbers of carers benefiting is not available.
- The Local Authority and the Local Health Board also fund 'Crossroads, Caring for Carers' a service that mainly provides replacement care at home. The LA contribute £194,000 and the LHB £57,600. Together these amount to approximately 22,660 hours of care at home. The frequency and duration of domiciliary care vary according to individual carers' needs. Day care provision cannot be split for the reasons mentioned above and in addition consideration has to be given to the intended outcomes from the services. Day hospital provision by its nature is interventionist and thereby benefits the service user. Day care provides for service users who live independently as well as those with carers at home. Access to day services is currently by means of a community care assessment.

### **Carers' Grant Funding**

The Carers Grant represented a ring-fenced resource for carers, which was provided to the Local Authority by WAG to support the implementation of the National Carers' Strategy in Wales - £399,085 in 2005–2006. The grant targeted providing carers' breaks in the main and was accessible through the process of a detailed plan each year. The grant transferred into the Revenue Support Grant in April 2006. In recent years the grant has been used, in the main, for its designated purpose - breaks for carers. This has been achieved by allocating grants to voluntary sector organisations that provide services for carers enabling them to have a break. These are:

- Crossroads Caring for Carers
- Alzheimers Society
- Amman Valley Dementia Care Support Group
- Hafal
- Megan and Trevor Griffiths Trust
- Llanelli Gateway

Together these organisations provide a variety of short breaks that range from centre based day care to domiciliary replacement care services and account for £236,500 of the grant. In addition the funding provides small grants to carers who have received an assessment of their needs – the Flexible Support Grant scheme. Grants average £200 and can be used to assist with a break or to purchase facilities or services that help the carer to sustain their role (most request financial help to have a break). £50,000 provides assistance to some 250 carers each year.

The Stroke Association and Mencap receive £31,348 and £15,710 respectively to provide family/carer support. These services offer information, signposting and advice that helps carers to manage change in their lives and advise them how and where to access additional support. Barnardos run a countywide Young Carers Project that focuses on young carers with acute needs in terms of development and emotional support. This service receives £34,839 from the grant. A small grant of £3,000 is allocated to the Parkinson's Disease Society to help carers have social opportunities. The remainder is used to provide 50% funding for the Joint Carers Development Officer's post.

The transfer of the Carers' Grant into the Revenue Support Grant went smoothly after an option appraisal was presented to the Divisional Management Team and agreement reached.

In March 2006 the Minister for Health and Social Care announced a further £3 million to support carers of people with mental health problems and especially carers of people with dementia. Carmarthenshire received £202,000 of this money in September 2006 and has allocated it to support further help for this group of carers.

### FUNDING IMPLICATIONS OF THE CARERS' STRATEGY

The Carers' Strategy has been designed to set realistic and achievable outcomes. The majority of actions can be implemented within existing budgets but will require greater commitment from service providers to incorporate carers' issues into their day-to-day functioning. There will be an obvious capacity issue to address as teams are required Towards a Better Lifestyle for Carers – Carmarthenshire Carers Strategy and Action Plan January 2007

to meet the emerging demands of the Carers (Equal Opportunities) Act 2004. The Act places a duty on the local authority to inform carers of their statutory rights to assessment and to offer assessment where it is required. In turn, the needs identified during the process of assessment will have to be given due consideration. Additionally the Act places a duty on the authority and its partners to assist carers in maintaining a life of their own, whether that involves helping them to stay in work, go back to work, to pursue leisure activities or to access training or education.

Recognising the potential demands on service provision and the present level of carer inclusion has influenced this initial plan to concentrate, in the main, on improving awareness, recognition and the identification of carers across and within all service provider areas.

The development of a team of Carers' Support Workers across Carmarthenshire will help to implement this strategic action plan and the new Act and provide a wide range of localised support for the 22,000 carers in Carmarthenshire.

Table 1 below illustrates the annual costs and the total cost for this strategy as well as the ongoing costs for those services established by this strategy.

**Action 1** – identifying and recognising carers, includes the costs of a poster campaign, an aide memoire and, significantly, the promotion of young carer identification. Awareness raising, training and involving carers, will need resources to help with the costs incurred by carers.

**Action 2** – information for carers, requires funding to provide the Carers Project with half time administrative support and set-up costs for this.

**Action 3** – breaks for carers, requires funding to provide 'I am a carer' cards for carers that will help them in emergency to get help for the person for whom they care.

**Action 4** – Carers' Support Workers – funding to be sought from external sources in partnership with voluntary sector organisations.

**Action 5** – opportunities for carers, attached costs are for the purpose of facilitating the participation of carers in the development of new policies and service developments.

ACTION	Costs (New funding required)				
	Year1	Year 2	Year 3	Total	On-going
Identifying and recognising carers	£8,500	£8,450	£8,450	£25,400	TBC
2. Information for carers	£13,000	£13,000	£13,000	£39,000	£13,000+
3. Breaks for carers	£500	£500	£500	£1,500	ТВС
4. Carers' Support Workers	To be sought	To be sought	To be sought	To be sought	To be sought
5 Opportunities for carers	£2000	£2000	£2000	£6000	твс
TOTAL	£24,000	£23,950	£23,950	£71,900	твс

### **APPENDIX 2**

# SUMMARY OF THE CONSULTATION REPORT

The public consultation on this strategy took place throughout the summer of 2005. The draft document contained a pro forma for completion, asking for views on overall impression, readability, comprehensiveness and emphasis and also invited further comments.

In all 109 responses were received and 6 further letters giving extended feedback.

The overall impression of the document was positive with 93/108 rating it good or very good. Readability was rated good or very good by 80/100 and 85/105 felt the document was easy to understand. Just over half of the respondents felt that the document has all the aspects of being a carer and the same number of respondents felt satisfied that the emphasis was right. Those who were not satisfied (approximately a quarter) felt that important aspects of being a carer had been left out and the same number of respondents said the emphasis was not right.

Main themes emerging from comments received were:

## Readability

- Too much jargon and too many abbreviations making it difficult to understand by a lay-person;
- Too much information and overwhelming.

## **Availability**

Suggestions were received to increase availability through:

- Creating a database of carers for mailouts;
- Website:
- Statutory service workers.

### Comprehensiveness

Those respondents who thought the draft was lacking aspects of being a carer suggested:

- Carers stress levels are a health and safety issue;
- Vulnerable carers those who are elderly, sick, disabled or young;
- Unfair benefits system:
- Lack of round the clock support for all service areas;
- Data protection issues;
- Lack of flexibility and understanding when carers require help themselves (eg GP appointments):
- Need for more Carers' Support Workers, sooner:
- The different needs of rural and urban carers.

# **Neglected aspects**

- Carers needing to maintain or return to work;
- The stress on families when a member is expected to undertake a caring role;
- Being pressurised to take on care;
- Time taken to process grants for carers.

# Respondents making additional comments suggested:

- Making the document more accessible and readable;
- Feedback from the consultation via a newsletter;
- Standardised referral system for carers;
- Concern that words would not become actions.

# **APPENDIX 3**

# **GLOSSARY**

Advocacy	Representing others
Aide-memoire	A tool to help people remember
Audit	The process of official examination
Carers' Assessments	A right to have carers' needs thoroughly examined so that, where possible, services can be provided to help meet carers' needs
CCC	Carmarthenshire County Council
CAVS	Carmarthenshire Association of Voluntary Services
ССР	Carmarthenshire Carers Project
DPPC	Director of Planning and Primary Care
ECS	Education and Children's Services
GP	General Practitioner
JCDO	Joint Carers Development Officer
JCOCS	Joint Commissioning Officer – Children's Services
LA	Local Authority
LHB	Local Health Board
MARG	Multi Agency Reference Group for Carers
NHS	National Health Service
Performance Indicators	Statistics that convey information about services
Performance Management frameworks	Methods for collecting and analysing data
Primary Care	Doctors' surgeries and other community based services
SC & H	Social Care and Housing
Secondary Care	Hospital based services
Siblings	Brothers or sisters
Signposting	Directing people to other services
Social inclusion	Making sure that all groups in societies or communities have equal opportunities
SPOCS	Senior Principal Officer – Children's Services
Standards of practice	Minimum levels of service agreed by accountable staff
YCP	Young Carers Project