

Cardiff Carers' Plan

"Improving the quality of carers' lives"



*Produced in partnership with the Cardiff Carers' Forum,
Cardiff Local Health Group, Cardiff Council, Cardiff & Vale NHS Trust,
Cardiff Carers' Centre & Carers' Development Project.*

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"Carers in Cardiff have always been in the forefront of the Carers movement, working towards support for the Carer, so it is with delight that I endorse this plan on behalf of the Carers Forum. Carers welcome this recognition and support of their unpaid role in caring for others. We are grateful for the co-operation that went into the formation of this plan and look forward with confidence to the implementation of this vital strategy by all the organisations involved."

Sheila Curran
Chair: Carers Forum

"The Carers' Centre welcomes the Carers' Plan as a positive step forward in the recognition and support of all Carers in Cardiff. It looks forward to working in partnership with the statutory authorities and other voluntary organisations in its implementation."

Sue Hutton
Facilitator: The Carers Centre

"Carers and Carers' organisations, in partnership with statutory authorities, have played a vital role in developing the Cardiff Carers' Plan, which provides a strategic framework for developing services and support for Carers in Cardiff now and in the future. Carers issues are now firmly on the agenda of many local agencies who are keen to offer support to Carers as users of their services or as employees."

Grahame Howard
Carers Development Project

"Cardiff Council is proud to have taken a co-ordinating role in this very important plan for Carers. The commitment shown by the all agencies involved is a testament to what can be achieved when people work together towards a common goal. I am confident that the implementation of the Plan will be beneficial to Carers on a practical level and will be the beginning of an important process in improving the quality of Carers' lives."

Cllr Chris Bettinson
Cabinet Member (Families & Health)

"I am absolutely delighted to provide my endorsement to the Cardiff Carers Plan. It has been a thrilling experience seeing it grow from the enthusiastic and dedicated activities of Carers into a Plan that provides so much opportunity. As we move into a broader health and wellbeing agenda I am sure that a momentum will build up that will ensure that the needs of Carers will be increasingly recognised and supported. All stakeholders have supported the Plan and I am sure that all stakeholders will actively play their part in ensuring that it is put into operation."

Robert Jones
Chair: Local Health Group

Cardiff and Vale NHS Trust recognises the vital role of Carers to individuals and the population and is delighted to be able to support the aims and values of the Cardiff Carers Plan.

The development and maintenance of good working relationships with voluntary and statutory organisations is especially important to the Trust and we look forward to being able to work in partnership with other organisations to look creatively at practical ways of supporting this hard working group."

Stephen Harries
Director of Development
Cardiff and Vale NHS Trust

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Foreword

"I have cared for my 38 year old daughter for over 25 years. I had to deal with a highly intelligent girl suddenly having several major epileptic fits a week and dozens of small seizures. Later she developed schizophrenia as well as becoming so psychotic that her life was full of fear, waking up in the middle of the night to ask me to stop the maggots eating her brain. At one time the only way of expressing herself was through violence.

Eventually I had to give up my job. You find it is very difficult to have a life of one's own under those conditions, but you know and I know that we should have that right. The right to have a life of one's own, the right to work."

**Sheila Curran MBE
Chair of Cardiff Carers' Forum**

"There is a very real role for prevention although this is difficult to justify in an environment driven by the political dogma of targeting those in greatest need - you may say how can you argue with that - but I would say you can...."

"People aren't always ready to accept help when it is offered. If people say no, the procedure says close the case. Could we not build in a review after 6 months and see if the Carer has changed their mind?"

"It's a bit like a 3 legged milk stool - health, social services and Carers - all three are needed or it will fall over"

**Dr Charles Twining OBE
Clinical Director of Psychology Services,
Cardiff and the Vale NHS Trust**

"What is needed is a schools campaign, a publicity campaign and to get Social Services, the NHS and the Benefits Agency all talking to each other because it doesn't matter who identifies Carers but that they are identified"

**Dr Andrew Dearden
Local GP & Chair BMA Medical Committee**

Speakers at both Cardiff interagency Conferences held in the development of this Plan.

"Carers devote large parts of their own lives to the lives of others - not as part of a job, but voluntarily. And often in addition to working themselves. For the sick, the frail, the vulnerable and the elderly, Carers provide help and support in ways which might not otherwise be available. By their effort, their patience, their knowledge, their understanding, their companionship, their determination and their compassion, Carers very often transform the lives of the people they're caring for - even if the difficulties they're grappling with still remain. Carers are among the unsung heroes of British life..."

**Tony Blair, Prime Minister
Caring About Carers, a National Strategy for Carers
February 1999**

Values and Principles

- The Cardiff Carers' Plan recognises the commitment and hard work of around 30,000 people in Cardiff who look after family members or friends who are ill, frail or disabled. These people, who do not receive payment for their effort, are called Carers.
- It has been created in partnership with Carers and aims to improve the quality of Carers' lives and the people they care for.
- The plan supports a commitment by the local authority, the Local Health Group, Cardiff and Vale NHS Trust and voluntary sector partners to support and assist Carers in being able to continue to care in a safe and supported environment.
- The plan focuses on the needs of Carers, the Carers' perspective and adopts a multi agency approach in addressing the issues raised.
- The actions outlined will contribute to other major planning documents of Cardiff County Council, Cardiff and Vale NHS Trust, Cardiff Local Health Group and the Local Health Alliance. It will also influence the overarching Community Plan for Cardiff.
- Principles of equality will be central to this plan in order to reflect the diversity of Carers and their needs.
- A comprehensive and creative approach will be taken in looking at issues affecting Carers. New ways of working and greater flexibility in current services will be encouraged.
- This plan promotes the involvement of Carers at all levels by reducing barriers to participation.
- Organisations endorsing the plan will work towards Carer-friendly employment practices.
- This plan is part of a continuous process and will be monitored and further developed in partnership with the statutory and voluntary sector organisations and Carers.

I. Introduction

The aim of this plan is to begin the process of improving the quality of Carers' lives.

This plan has been developed through consultation with Carers and professionals working in all areas of health, the local authority and the voluntary sector. This included two conferences for health and social care staff, and a series of consultation meetings with other specific interest groups. A summary of the consultation and participation process is given in Appendix I.

Partners involved in developing this plan recognise that this is the first step in a long journey working towards a position where Carers feel valued as equal partners in the provision of care and are sufficiently supported in their role. "This plan provides a critical framework for statutory and voluntary sector organisations to work towards this aim and an effective way of monitoring and evaluating progress." (Rob Jones, Chair Local Health Group).

This plan is also a useful tool for encouraging and sharing good practice: user and carer involvement in EMI services within the Trust being an example of this. The implementation process involves joint working in several key areas which will continue to build on this partnership working.

Focus of the Cardiff Carers' Plan

The National Assembly for Wales, through consultation with Carers, published *Caring about Carers, A Strategy for Carers in Wales*. This strategy identified the following priorities for action: Health and Social Care, Information, Support, Young Carers and Employment.

The Cardiff Carers' Plan aims to build upon these major themes by recognising and acknowledging the needs of local Carers. Additional areas of focus identified locally are as follows: Skills Development, Awareness & Recognition, Transport, Participation and Consultation, Joint Working and Equal Access.

This plan looks at the diverse needs of Carers in all situations and also recognises and discusses specific issues relevant to: Young Carers, Parent Carers of disabled children, Carers of people experiencing mental health problems, Older Carers and Minority Ethnic Carers.

A further plan relating more particularly to the needs of young Carers will be developed in the future.

Background

Profile of Carers

The General Household Survey of 1995 indicated that one in eight people in the U.K. is now a Carer. Therefore, we estimate that there may be around 35,000 Carers living in Cardiff. In addition, a recent Carers' National Association survey of members found that that 85% of respondents were providing over 50 hours care per week, with 70% stating that they were caring for over 100 hours per week. Nearly half of the Carers surveyed also combined their caring role with paid employment. The census of 2001 contains a Carer question and should provide clearer local information.

Some Carers live in the same house as the person for whom they care. Others live nearby and visit regularly. Some live a distance away and visit weekly or monthly. Some Carers provide care for limited periods of time or as part of an informal support network. Some provide care for more than one person. Caring often impacts on the whole family.

The need for care can arise in different ways. Sometimes a person's need for care increases gradually, perhaps as they grow older and frailer, or perhaps because they are suffering from dementia or a similar progressive condition. Carers of people in these circumstances may find themselves gradually giving more and more help as the days go by. They may not even notice that the stresses and strains of caring for almost 24 hours a day are beginning to affect their health.

People who provide care for others are a very diverse group, with diverse needs. A man of 70, caring for his wife with Alzheimer's Disease during all her waking hours, may have very different needs from the 30 year old parent of a severely disabled child, from the 40 year old wife of someone who has suffered a head injury in a road accident, or from a child of 14 whose single parent has mental health problems.

It is important to recognise that caring takes place within the context of a human relationship and this is an extension of that relationship, not something separate, special or different. The relationship, as much as the caring task to be performed, is what shapes the experience of caring and which should influence the kind and amount of support that people need.

Caring involves a mixture of difficulties and rewards, or even pleasures. All too often we look for the difficulty, the burden, the stress of caring - but we also have to acknowledge that Carers are not all the same. Research has shown that support for Carers is more effective if it builds on the unique mixture of difficulties, burdens and rewards that are experienced by individual Carers. The services and support offered need to reflect this.

Carers and Social Exclusion

Social exclusion is a reality for many Carers. There are a variety of ways in which people can be denied full participation in their neighbourhoods, communities and more generally in society. It is also very much about the degree to which groups of people are being excluded from participation in daily life and activities that many of us take for granted. They lack full access to services, to leisure, to paid work, to the political processes; they find themselves outside the mainstream of society.

Carers' vulnerability to social exclusion can be considered in a number of ways:

- no source of independent income
- long-term receipt of benefits
- living in families with very high costs of disability and/or care
- caring for person/s who have conditions/illnesses which carry a high level of social stigma such as AIDS/mental health problems/substance misuse
- caring full-time
- self reporting difficulties in managing financially
- own limiting long-standing illness or disability
- not had a break since started caring.

Many Carers are likely to be affected by any combination of these factors and, therefore, are probably at risk of double or treble the jeopardy of vulnerability to social exclusion.

2. The Diversity of Carers

(i) YOUNG CARERS

Young Carers are children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. They provide similar levels of support to adult Carers but their experiences differ because those under the age of 18 are legally defined as children and, as such, should not be expected to take on significant or substantial caring roles. However, community care policy and legislation have up to now assumed that family members will provide the bulk of care in the community with the state stepping in to fill the gaps. In some families, this results in children and young people adopting caring roles often, though not exclusively, in the absence of another adult in the home.

The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem, substance misuse problem or other condition connected with a need for care, support or supervision.

Factors that influence the extent and nature of young Carers' tasks and responsibilities include the nature and extent of illness or disability, family structure, gender, culture, religion, income and the availability of professional support and services.

Where children and families lack appropriate professional support and adequate income, some young Carers experience impaired psycho-social development, including poor educational attendance and performance, and restricted peer networks, friendships and opportunities. These will have implications for their own adulthood.

Not all children with ill or disabled parents will become young Carers. Some families will only need assistance for short periods of time when a family member is acutely ill, but others will need more long-term assistance. With the provision of adequate support, services and finances, most children will not be adversely affected.

The Cardiff Carers' Plan acknowledges research which has indicated that there may be as many as 300 young Carers in Cardiff, and that the average age of young Carers is 11 years. The plan also recognises and acknowledges the often hidden and complex nature of the lives of young Carers and that a range of co-ordinated approaches is needed in order actively to identify and support young Carers. The approach will involve the integration of a range of Adult and Children's services to meet young Carers' needs comprehensively.

In order to begin to look for effective ways to address the specific needs and issues facing children and young people who are Carers, it is intended to develop a separate and distinct strategic Cardiff Young Carers' Plan.

(ii) PARENT CARERS OF DISABLED CHILDREN

The caring responsibilities of parents with disabled children are over and above those of normal parenting. The needs of Carers of disabled children are likely to vary during their child's development. Key periods of stress are likely to occur at times of transition: starting school, transfer from primary to secondary school, and the transition from adolescence to adulthood. Parent Carers are likely to spend the longest time caring. The cumulative effects on emotional and physical health need to be considered.

Caring for a disabled child has been described as "a life-long game of snakes and ladders". Although parents are sometimes faced with what seem like insurmountable problems, these are invariably balanced by good things that happen such as unexpected achievements which give enormous pleasure.

Many parent Carers say that one of the hardest things about having a disabled child is the constant struggle to be as ordinary a family as any other, and for their children to be accepted on equal terms with others. Families who have not come across disability at a personal level before may need to start using services and benefits of which they were previously unaware. Information about services is an important first step in getting the support that is needed. Finding out as much as possible about a child's condition, any available treatments and ways of helping such as physiotherapy or speech therapy, can be important in helping parent Carers come to terms with the disability and in accessing available support services.

"Parent Carers need adequate, flexible and reliable respite care which can meet the needs of people with profound and multiple disabilities. Carers should have the right to an automatic assessment of their needs and joined up services where all the professionals talk to each other and are aware of the service users' and Carers' needs without having to undertake numerous visits and assessments. More training for professionals in dealing sensitively with service users' and Carers' needs would be good.

Recognition of parent Carers' need for support to access the workplace is vital. A one-stop shop for advice and information and a comprehensive directory of services would also be useful. Parent Carers also need to be directly involved in the planning and development of services. We would also like the opportunity to discuss the future care needs of our loved ones, there should be a strategy to provide the care when we are no longer able to..."

Norbert Flynn & Pauline Young

Cardiff & Vale Parents' Federation for People with Learning Difficulties

The experience of each family is unique and special. Families caring for disabled children need support services geared to individual family needs and most families prefer services integrated with those for other children and families. This has been recognised in both the Children Act and the Carers and Disabled Children Act.

(iii) CARERS OF PEOPLE WITH MENTAL HEALTH ISSUES

Carers of people with a mental illness often find their caring situation to be very hidden as the nature of a mental illness can in itself sometimes be almost invisible. This situation is further compounded by the social stigma attached to mental ill health and, in this way, such stigma also becomes an issue for the Carer. The vast majority of people caring for someone with a mental illness do not recognise themselves as a Carer, as the physical aspects which are so often associated to other caring situations are not always apparent. However, the impact upon the quality of life of the individual Carer and the family as a whole is often no less dramatic.

Mental illness is not necessarily constant, and it can be episodic or even cyclical. People who are caring for someone with a mental illness, through their extensive personal knowledge and experience of that person, often spend much of their time actively preventing the next episode or crisis. Carers often say that they feel as though they are "walking on eggshells" and that, as a result, they are unable to get on with their own lives. Carers often feel as though their lives have also been taken over by the illness and feel anxious 24 hours a day 365 days a year. As a result of this, coupled with frequent sleepless nights, the Carers' own mental health can suffer dramatically.

People caring for an adult son or daughter with a severe mental illness also sometimes feel a sense of loss and may grieve not only for the person they feel they once knew, but also for the loss of their child's personal potential and individual aspirations. If an illness is of a genetic nature, a situation that may influence a person's individual decision about having children, there is also the possibility of Carers experiencing a feeling of loss of future grandchildren.

"We felt so alone and afraid. We did not know how to help our relatives and we did not know what to say to them or do. There was no information about diagnosis or treatment. We spent years waiting for a full diagnosis and then there was no follow up information or training in dealing with the condition or the medication. Health and Social Services really should view family Carers as equal partners.

Now there seems to be no chance of a break, no one to talk to when we need to and no outside help. Sometimes we just need to get away. There is a need for proper support in the community, which is holistic and proactive in order to prevent, as far as possible, future episodes of mental ill health..."

**Linda Howlett
Carer - Adult Mental Health**

"Carers are too often seen as part of the problem, and we are often told that we are over-protective. GP's and other health professionals sometimes don't listen to the Carer in relation to the patient, even though it is often only the Carer who knows what is really going on at home. Similarly GP's and other health professionals often don't recognise Carers or their health issues, and often certainly don't understand mental illness. There is a need for better training in this area.

The social stigma attached to mental illness makes us keep it all to ourselves, therefore it is difficult to speak to friends or family for support. It is a great relief to belong to the Carers' group where I can speak to fellow Carers. It is so difficult to get a respite break because often, people with mental illness find it difficult to accept any outsider other than their Carer..."

**Joy Lock
Carer - Adult Mental Health**

Access to help can also be affected by the specific nature of a mental illness. Carers are often excluded from medical discussions due to the need for patient confidentiality and, therefore, can feel disempowered. In this way, confidentiality can actually become a barrier to the Carer in supporting their relative. A rapid diagnosis is needed, closely followed by information and training for the Carer.

Carers of people with mental illness would clearly benefit from better mental health services. All mental health service users should have a care plan and a key worker. Emergency provision for support, respite and a 24-hour telephone help line are needed. Carers would like to have easy access to counselling for themselves, an advocacy service and befriending scheme and a Carers' support worker in hospitals. Carers have also identified a need for an open access centre for mental health service users and Carers, a friendly place where people could have time-out if needed, get an assessment and some support, information and advice on housing, benefits, medication issues and adult education opportunities.

Mental health Carers also need support to access work and would like to see more supported employment opportunities for people with mental health issues.

(iv) OLDER CARERS

Successive Welsh Health Surveys have shown that most Carers are aged between 45 and 64 years. However, it is estimated that one in four Carers is aged 65 or over. The Carers' National Association estimated that one in twenty Carers may be aged over 80 years. The U.K. National Carers' Strategy states that 2 out of 10 Carers care for a partner or spouse and that 4 out of 10 care for a parent. Older people who need care and who are married, are much more likely to receive that care from their partner than from anyone else. One half of all Carers look after someone aged over 75. Therefore, it is clear that there are a large number of older Carers caring for older people.

Consultation with Mencap also reveals a picture of Carers over 75.

"As an organisation we have noticed that quite a high proportion of our parent/Carers are over 75 years. Many of these people have spent their entire lives caring for sons and daughters, some of whom have profound and multiple disabilities. Many of these Carers are anxious about their own futures and of their own children they care for."

Gill Harris, District Officer

(v) MINORITY ETHNIC CARERS

It is anticipated that the next Census will show Cardiff with a minority ethnic population of around 10%. Cardiff has many different communities including amongst others, Afro-Caribbean, Bangladeshi, Chinese, Somali, Indian, Pakistani, Yemeni and Greek. Caring takes place within all these communities in much the same way as the majority community. However, the difficulties for Carers within minority ethnic communities are compounded by the following factors:

- a) these communities do not access existing services for the cared for person which mean the task of caring is primarily on their shoulders since there is little or no outside help
- b) the few services and sources of information that currently exist are mainly provided in English or Welsh.

Consultation

There is currently no organised network of minority ethnic Carers so the consultation that took place in preparing this plan was in a way a positive step for the communities that took part. The main issues raised through the consultation are as follows:

Information

Language is a huge barrier to accessing services. There is a need to raise awareness of services, not simply through translations, but through other means, e.g. videos. Verbal communication was considered important to inform people as illustrated by the work of the few community advocates employed.

A comment was also made about translating information being a waste of resources if there were no appropriate services in place.

Service Issues

1. People will only use services where they "feel they fit". Current services were viewed as not appropriate due to the lack of other minority ethnic people both as staff and service users. Day centres and domiciliary care services were used as examples.
2. A Minority Ethnic Carers' Centre where people could go to gain information and seek advice in their own language was thought to be vital.

Perception of Minority Ethnic groups

Incorrect assumptions are often made by authorities. A significant example is the assumption that minority ethnic people are always part of an extended family so there will naturally be a Carer within the household. This is no longer the case as many people live alone.

Young Carers

There are also issues relating to young Carers within the Black and Minority Ethnic communities. One member talked of her experiences as a young person looking after her sister, unaware of any help. Not being able to speak English was a huge barrier. It was only when she met a social worker who could speak her language that her situation changed.

Overview

There is a general lack of information on services for ethnic minorities which currently exist - irrespective of whether they are appropriate. There was recognition too that not all people read their own language so verbal communication was vital. The work of the health and social care advocates was seen as vital in providing information to people where language was a barrier.

The need for a place to go for information, to meet people of who could speak the same language and understand their culture was raised by all minority ethnic groups consulted. Knowing there would be a Chinese worker or Greek worker at an advice centre on a Thursday afternoon every week, for example, would provide a valuable service for sign posting and for advocacy work. This currently falls on the shoulders of a few people who take on this role over and above their normal work.

3. Life After Caring

When the cared for person moves into residential care

Caring does not necessarily end when a person moves into residential care, rather the nature of the role changes. Many Carers feel just as strong a sense of duty to care about, rather than for, the person after the move into residential care. Many Carers feel guilty that they have failed in some way if the person they are caring for goes into residential care and, at the same time, relief that the pressure of caring has been lifted.

When the cared for person dies

The Cardiff Carers' Plan recognises that Carers continue to need information and support in order to enable them to achieve a good quality of life after their caring role has ceased.

Some people may have been a Carer for many years and others only for a short time. The person they care for may be their spouse, partner, parent, child, brother or sister, friend or neighbour. They may have been young or old, with any kind of illness or disability. Whatever the situation, the Carer's own needs and concerns will be very personal to them and different from everyone else's.

Health and social services need to be sensitive to the emotional and physical health needs of Carers after caring ceases. This is often the time when a Carer's health may suffer most, especially when the caring stops abruptly following a period of intense stress and high level of support.

All agencies should support Carers through the difficult period many experience after their caring role ceases. Many Carers who have been members of support groups will continue to benefit from the support offered by such groups after caring ceases.

Carers returning to work

Carers who may have given up paid work in order to care may wish to return to the workplace following caring. Many of these Carers, particularly those who have been caring over a long period of time, will need support in doing so. Support in areas such as confidence building, education and skills development will be vital in enabling some Carers to return to work.

Carers as advisors & campaigners

Whether caring ceases due to bereavement or because the person moves into residential care, the skills and experience gained need to be recognised in order that they may benefit other Carers. Many former Carers welcome the opportunity to take on an active role, such as sitting on the committee of a voluntary organisation or advisory panels in planning health and social services, and they should be supported in doing so. Some former Carers have devoted their time to lobbying and campaigning for positive change for carers.

It is a fact that Carers themselves put Carers on the political agenda over the past ten years resulting in the Carers and Disabled Children Act which allows services to be provided directly to Carers. At a recent conference, the Chair of the Association of Directors of Social Services, Andrew Cozens, cited Carers as one of the most powerful voluntary sector campaigning forces, next to the Child Poverty Action Group.

Carers are, therefore, a powerful voice and useful partners in developing new health and social care services.

4. Carers' Legislation

The Carers (Recognition & Services) Act 1995 which came into effect on 1st April 1996, was the first piece of legislation to recognise fully the crucial role played by Carers. The Act contains two main elements for Carers:

- A Carer's right to ask for an assessment of their ability to care
- Local authorities' duty to take into account the results of this assessment when looking at what support to provide to the person cared for (the service user).

The Act covers three groups of Carers:

- Adults (people aged 18 or over) who care for other adults
- Adults who care for ill or disabled children (under the age of 18)
- Young Carers under the age of 18 who care for a relative.

To be eligible for an assessment, Carers must be:

- Providing, or intending to provide, a substantial amount of care on a regular basis.

Under this Act, an assessment is available on request when a local authority carries out an assessment of the person cared for in respect of services under:

- The NHS & Community Care Act 1990
- The Children Act 1989
- The Chronically Sick & Disabled Persons Act 1970.

The Carers & Disabled Children Act 2000, implemented in Wales in August 2001, aims to build upon the Carers Act of 1995 and to give local authorities new and important powers to provide services directly to Carers. This legislation is intended to enable local authorities to develop new services to support Carers. It will offer help to Carers who need practical support to continue caring by making it easier for Carers and disabled people to get services that will enable both to have a better quality of life.

What the new legislation will do for Carers:

- Give Carers, over the age of 16, the right to an assessment of their own needs, even when the cared for person does not want to be assessed
- For the first time, local authorities will be able to provide Carers with services in their own right. Services to Carers are not defined as such. Local authorities may provide any services which, in their view, will support the carer in their caring role and help them to maintain their own health and well being. These services are, however, subject to charging arrangements

- Local authorities will be able to provide vouchers and direct payments to Carers and disabled people so that they will have more freedom to choose the types of services they require
- Young disabled people aged 16 and 17 will be able to receive direct payments to purchase their own support services to meet their assessed needs under the Children Act 1989. This is intended to bring about improvements in the quality of life of people who would like to manage their own support.

The Assessment

A Carer's assessment under The Carers and Disabled Children Act 2000 is carried out at the request of the Carer in order:

- To determine whether the Carer is eligible for support
- To determine the support needs of the Carer (i.e. what will help the Carer in their caring role and help them to maintain their own health and well being)
- To see if those needs can be met by social or other services.

The assessment should be a Carer-centred process, listening to the Carer, valuing their experience, focusing on outcomes that the Carer thinks are important in terms of supporting them in their caring role or maintaining their health and well being. It is also the point at which a Carer may wish to raise whether their caring role is a sustainable one. It should be a pragmatic process focused on identifying the best possible outcome for the Carer, within the context of a rounded assessment of the caring situation. This may also be a point at which a Carer begins to express doubts about their ability to continue to care. The assessment must value the Carer's views and start from what the Carer thinks are the most important issues. At all points, practitioners should recognise Carer's knowledge and expertise. Any solutions and service options should be negotiated with the Carer rather than imposed.

Outcomes for the Carer could be delivered in a number of ways:

- Advice, information or social work as part of the care management process
- A modification of the package for the cared for person that provides the Carer with, for example, additional breaks or the delivery of additional or more convenient community care services to the cared for person
- The provision of "Carers' Services" through the Act
- Sign-posting to community services that the Carer can access directly and that are free of charge (such as Carers' centres and support groups).

Under the Act, Carers have a right to ask for an assessment. Good practice advocates that local authorities should have a policy of offering Carers an initial assessment in circumstances where the Carer is providing support to a community care service-user.

It is not only the time spent each week caring that has an impact on Carers. For some, such as those caring for disabled children or adults with learning disabilities, the caring role can have the additional impact of being a life long commitment. For others, such as those caring for adults with severe mental health problems, caring can be a sporadic or cyclical responsibility. The Carer may not be physically or practically caring at all at certain times, but still be anxious and stressed waiting for, or actively seeking to prevent, the next crisis. In addition, caring responsibilities may conflict with other family responsibilities, such as parenting or holding down a job. Any assessment of the Carer's need for support has to look at the whole caring situation.

5. Identifying and tackling the issues raised by carers

(i) CARERS' HEALTH

It is widely recognised that Carers are particularly vulnerable to depression and emotional stress and that there is a direct link between this and the long-term nature of caring. The Welsh Health Survey of 1998 shows that Carers in all age groups are more likely than non-Carers to be classified as 'at risk of depression.' Over 50% of Carers suffer from back injuries and depression as a consequence of their caring roles, (Ignored and Invisible - Carers' Experience of the NHS, Carers' National Association 1998).

Health and social services have a critical role in -

- identifying Carers and the contribution they make
- assessing their needs alongside those they care for
- providing services that are responsive to their particular circumstances
- promoting the health and wellbeing of Carers
- promoting awareness of Carers' needs
- supporting and promoting Carers' networks and the voluntary sector.

Issues identified by Cardiff Carers:

- the health care needs of carers as individuals need to be addressed. This could be through a "well carers' clinic." In terms of information and sign posting, the idea of a Carers' Champion in each GP surgery was suggested
- professionals need to be made aware of Carers' health needs and issues
- there should be acknowledgement of specific issues around mental health. Diagnosis can be over a period of years, information needs be given at the right time and the language used by professionals at the time of diagnosis is important
- preventative health care is important in maintaining a Carer's ability to care
- access to counselling is needed
- time for, and access to, basic treatments such as chiropody and dentistry
- there is a need for more respite care, particularly for children.

Wider issues:

- influence GP training re Carers' issues
- ensure Carers are on the agenda of the Local Health Alliance and Local Health Group

Action Points

- 1) Promoting health will be high on the agenda for all agencies. This will include: more widespread use of GP referrals to leisure centres, offering Carers particular courses, discounts in leisure centres and skills development, e.g. back care, stress management.
- 2) The possibility of developing Carer Clinics to monitor general health and act as an advice and sign posting system will be explored.
- 3) The provision of further counselling and support services will be explored.
- 4) The nomination of a "Carers Champion" in each GP surgery will be encouraged. It is acknowledged that this person will require support and an appropriate group will be established to facilitate this. The information group will act as an information resource for all nominated people to assist them in their role.
- 5) A bid has been developed by the South East Locality Steering Group for a Carers' Development Link Worker to support primary care teams in the identification of Carers in Cardiff. This bid has been forwarded to the Local Health Group's National Service Framework Steering Group for consideration.
- 6) The references to Carers' issues in current legislation and guidance, such as the NHS Plan (1), the National Service Frameworks (2) and the Audit report on Mental Health Services for Older People (3) will be taken on board and included in the Local Health Action Plan.
- 7) The participation of Carers in preparation of strategic development plans in the health service will be encouraged.
- 8) The work of Carers' Support Groups will be endorsed and promoted.
- 9) The development of Carers' suggestion schemes will be explored.
- 10) The establishment of a Carers' Interest Group within the Cardiff and Vale NHS Trust will be explored.

References

1. "Improving Health in Wales - A plan for the NHS with its partners", January 2001
2. National Service Framework for Older People, DH , March 2001
3. Mental Health Services for Older People in South Bro Taf - District Audit, 2001

(ii) ACTIVE SUPPORT

Carers need support in many forms: time, money, peace of mind and someone to talk to. Carers need someone who will listen in confidence to their concerns, fears, hopes and experiences; someone who will empathise with, and understand, their lives as Carers. A help-line is considered most useful. Young Carers (under 18) in particular need someone to be a friend to them on their own terms.

Carers' breaks (also known as respite services) are a key component in supporting Carers. The provision of breaks needs to be diverse, flexible, affordable and based upon the individual needs of both the Carer and the person being cared for, in order to enable Carers to take a regular break from caring. Time off from caring provides emotional help and allows the Carer to escape from stresses. The Breaks for Carers Scheme has been welcomed and on-going consultation about support with Carers will continue.

In the home, Carers need services such as home care to be regular, reliable and flexible to adapt rapidly to changing circumstances. Carers also need to be confident of both the quality and continuity of services in order to plan ahead. A more co-ordinated approach to joint working between health, the local authority and voluntary organisations would also benefit Carers.

Carers also frequently express concerns about the cost and availability of public transport and particularly the lack of provision of specialised transport to enable them and the person they care for to go out together.

Issues raised by Cardiff Carers:

- more breaks for Carers are needed
- respite services for children with multiple disabilities and continuing health care needs should be developed. These could include specialist foster carers
- advice & advocacy services needed
- further support for Carers' organisations
- disabled facilities, aids & equipment: these services should be easier to access and waiting times shortened.

Action Points

- 1) The local authority will develop the Breaks for Carers Scheme with continual involvement of Carers.
- 2) The local authority, with voluntary sector partners, will develop a Young Carers' club under the Carers' Special Grant as a starting point to providing specific services for this group of Carers.
- 3) Respite services for children will be developed under the Breaks for Carers Scheme and other initiatives implemented within Children's Services.
- 4) A strategic overview of advice and advocacy will be developed with all key stakeholders including the statutory and voluntary sector.

- 5) The local authority will continue to support Carers' organisations through grants and offering other resources whenever possible.
- 6) The process of obtaining disabled facilities grants and disability aids from both the local authority and the health authority will be examined and made more efficient and accessible.
- 7) The local authority, with partner organisations, will explore ways of making information and access to housing for people with disabilities and their Carers more efficient.
- 8) The Carers' Development Project will explore the development of a Carers' befriending scheme and Carers' support groups.

(iii) INFORMATION

The provision of easily accessible, relevant, factually correct information about both local resources and the benefits and tax system is of critical importance to Carers and Carers' organisations. Information needs to be provided in a variety of formats and languages to meet individual needs. A key issue is where the information is to be provided. Statutory and voluntary sector organisations have a key role to play in disseminating information to Carers.

Information is generally difficult to obtain as there is poor mapping and lack of knowledge of both needs and services. This makes access to existing services difficult. Information is best provided when it is comprehensive and does not just answer the question immediately posed since many Carers are not necessarily aware of, and therefore will not ask for, the full range of options that might be open to them.

Issues raised by Cardiff Carers:

- information is needed for Carers on a variety of issues including: welfare rights and the range of support services provided by the voluntary sector, local authority and the NHS
- Carers need information about their right to an assessment - many Carers are unaware of the legislation
- the way information is disseminated needs to be considered. A more proactive approach should be taken by statutory authorities, e.g. parents should be given appropriate information at the time of statementing. Carers should be given general information they can take their time to read, with the option to act upon when it suits them
- there should be a variety of access points for information and access to services
- everyone has a duty to provide information. Voluntary organisations which have few resources may need financial help producing information.

Action Points

- 1) An inter-agency working group will be set up to look at information issues identified by Carers. This group will co-ordinate many of the action points below.
- 2) A Joint Information Strategy will be developed which will include:
 - the information needs of minority ethnic communities
 - the ways and places Carers access information
 - the process within which professionals should provide information directly to Carers
 - the type of information currently available and ways in which any gaps in the information are filled.
- 3) A central point will be identified and developed to co-ordinate the work on information.
- 4) Further development of the Carers' Information Pack currently piloted within the local authority.
- 5) The development of a local web site for Carers.
- 6) Assistance will be provided to voluntary groups with few resources to produce information about their services.

(iv) AWARENESS & RECOGNITION

Many Carers do not recognise themselves as "Carers." Parent Carers identify themselves as parents first and consider Carers to be the people who look after their children in their absence. Carers of people with mental health problems also have difficulty in relating to this title since the care provided is often not physical but more supervisory, and they may not live in the same household. Young Carers are amongst the most hidden and possibly hard to reach group of Carers. Their need or desire for anonymity is particularly important in respect of any fears they may have of being separated from the person they care for.

Awareness and recognition that they are Carers as defined by legislation is important if they are to take advantage of the rights and services proposed under the new legislation.

Issues raised by Cardiff Carers:

- professionals need to recognise the importance of the role of Carers and have an awareness of Carers' needs as distinct from those of the cared for person
- Carers need to recognise that they are "Carers" - and feel proud of that role. It was acknowledged that there were difficulties in "making it public," because of the impact it may have, particularly within the work place
- Carers' assessments could be promoted as a way of enabling people to recognise themselves as Carers
- professionals need to recognise that "Young Carers", under the age of 18, exist and should be supported in a non-stigmatising way that sees them as children first.

Action Points

- 1) The National Strategy encourages GPs to identify Carers.
- 2) Carers' assessments will be promoted under the Carers and Disabled Children Act. These will be recorded on the existing client database. Information derived from the database could be useful in providing a more accurate profile of Carers in Cardiff.
- 3) The local authority will continue to run its Carers' Awareness programme presented by the Carers' Development Project for social care staff.
- 4) The information strategy will look at issues around Carers identifying themselves.
- 5) Work will be done in awareness raising and identifying young Carers across the local authority.

(v) SKILLS DEVELOPMENT

Many Carers express the need for training or advice in particular areas to enable them to care for the looked after person. For example, in terms of Carers' own health, knowing how to move a person safely is important in tackling the high incidence of back injuries. Similarly, stress relief techniques may assist Carers to manage the emotional element of their caring role. Professionals also need to develop their skills and the knowledge base in respect of Carers.

Issues raised by Cardiff Carers:

For Carers

- skills development should be provided in a variety of areas including: first aid, manual handling, infection control, food hygiene and safety, stress management, confidence building, introduction to caring, child care management
- training on the hospital ward and in the home should be improved by health professionals

For Professionals

- raise awareness of Carers' needs and issues to enable them to identify and support Carers on a grassroots level. Specific awareness raising will also take place around the issue of young Carers.

Action Points

- 1) The local authority will facilitate skills development through its central Human Resources Service and the Adult Education programme.
- 2) Training provided by health staff on wards and within the home will be examined and improved through further consultation.
- 3) The Carers' Development Project will continue to run a programme for local authority staff which could also be offered to health professionals.

4) The Carers' Centre will continue running the Carers' Awareness programme to GPs and other health and social care professionals.

(vi) EMPLOYMENT

"When my wife with MS was unable to take the children to school I was able to start work after I had done the school run."

Many Carers will be working when the need to care arises and most will wish to continue to work. Paid work is important to Carers for many reasons -

- financial independence
- covering the costs of caring
- an external focus and sense of satisfaction
- maintaining social networks and friendships
- self esteem

If Carers reduce their hours significantly or give up work altogether, the financial and emotional implications can be far reaching. Carers who stop work face an immediate reduction in income and the loss of companionship at work. Any period without pension contributions is also likely to have long term implications for financial well being. There is a clear business case for supporting Carers in work simply in terms of employers retaining experienced and committed staff. Employers can support their Carer-workers through Carer-friendly employment policies which enable flexible working hours where needed, combined with other forms of practical support such as access to a telephone at work and time off for emergencies without recriminations for the employee.

In addition, a recent government report entitled "Opportunity For All:Tackling Poverty and Social Exclusion" recognised that Carers are "more vulnerable to the problems of social exclusion; they are isolated from the rest of society because their caring duties tie them to their homes and they may face insecurity in old age because their working lives are disrupted."

Issues raised by Cardiff Carers:

- support Carers in employment by providing appropriate, flexible services
- support Carers in employment through Carer-friendly policies, local authority and health authority to take the lead and influence other employers
- promote the above
- assist Carers to gain employment, e.g. specific schemes, courses through adult education
- create a list of approved childminders for disabled children at the same rate as non-disabled children and provide training to enable this to happen
- look at the issue of after school clubs currently only open to children who attend school.

Action Points

- 1) Local authority and health authority to develop and promote Carer-friendly employment policies.
- 2) Local authority will consult with Carers in developing new adult education courses.
- 3) Children's Services will explore the possibility of creating an approved child minders' list of people able to look after children with disabilities
- 4) The issue of access to after-school clubs will be taken up with the Schools Service.
- 5) Service providers will look at existing services and, by consulting with Carers, examine their appropriateness and flexibility and make necessary improvements.

(vii) PARTICIPATION AND CONSULTATION

All agencies need to involve Carers actively in the planning and delivery of services. Carers should be represented at a strategic level of service planning and delivery for all client groups in order to ensure that the needs of Carers are identified and addressed. Carers need to be viewed as partners by all agencies in order to ensure full participation.

It is also important that participation and consultation is seen as a continuous process which does not stop or start when strategic plans are being developed.

Issues raised by Cardiff Carers:

- agencies should actively involve and consult Carers in service planning and delivery
- there should be an opportunity to discuss the future when the Carer is no longer able to care
- Carers should be involved in the future development of this plan.

Action Points

- 1) Develop a participation strategy which will encompass enabling facilities and resources such as crèches, alternative care arrangements, interpreting services and transport.
- 2) Any new joint planning processes will be devised in conjunction with Carers.
- 3) Barriers to full participation will be acknowledged and efforts will be made to provide information in "plain English/Welsh" and other formats as necessary. Cultural sensitivity will be exercised, the environment will be carefully considered and, most importantly, Carers will be viewed as partners.
- 4) Continue to work with, and promote, the Cardiff Carers' Forum.
- 5) Continue to consult with Minority Ethnic Carers.

(viii) JOINT WORKING

Given the diversity of needs of Carers, joint working between health, the local authority and the voluntary sector is an important component of any strategic plan for Carers. The Cardiff and Vale NHS Trust, the Local Health Group, the Local Health Alliance, the Community Health Council and the local authority all have an effect on Carers' lives. It is important that all agencies collaborate and take action on the proposals outlined throughout this document.

Issues raised by Cardiff Carers:

- there should be joint working across and within all sectors - private, public and voluntary
- there should be a partnership approach which will be cost effective, avoid duplication and waste
- the need for "joined up" services so that professionals involved "talk to each other" to get the full picture regarding Carers' needs
- children with multiple disabilities often have multiple assessments. A one stop process would be preferable in line with the new framework for assessment of children and families
- solutions to respite care could be tackled through inter-agency funding. Recent government legislation encourages this but action is needed to make this happen
- the issue of young Carers needs to be examined by a variety of relevant parties, e.g. Education, Social Services, Children's Services, Leisure and Lifelong Learning, the voluntary sector and primary health care.
- information on housing options needs to be brought together. More joint working in this area is needed.

Action Points

- 1) An inter-agency working group will be set up to co-ordinate the work around Carers. This will include representatives from the statutory and voluntary sector and Carers' groups.
- 2) A sub-group to look at particular issues around children with disabilities and resources for parent Carers will be established.
- 3) The establishment of a multi-disciplinary working party to formulate good practice in working with young Carers will be established. A separate Young Carers Plan will also be developed.
- 4) NHS & the local authority partners will work more closely to develop streamlined services, and with Carers in identifying areas of priority. In the longer term, this could link in with "Increased Flexibilities", (a new initiative of joint working between local authority and health services).

(ix) EQUAL ACCESS

It is important to ensure the availability of support and services for Carers of any gender, race, culture, disability, age and sexual orientation. Ethnic minority Carers have particular needs to be addressed as outlined earlier in this document.

Action Points

- 1) Access to information in other languages and other formats will be a key element within the information strategy.
- 2) The development of ethnic minority Carers' network and support groups will be explored and resources made available to facilitate this.
- 3) The work of community advocates and link workers employed by the local authority and the NHS will be reviewed.
- 4) The provision of a face to face advice service in community languages will be explored.
- 5) Devising more culturally appropriate services will explored.
- 6) Ways of making existing services more appropriate will be identified, e.g. advertising for minority ethnic staff within community based job centres.

6. Voluntary Sector Developments

Many Carers in Cardiff look to, and benefit from, the support offered by a broad range of voluntary organisations. Some organisations have a specific focus on Carers whereas others cater for Carers' needs within their more general range of services, for example, those for older people or people with mental health issues. Voluntary organisations offer Carers a diverse range of services: practical support such as domiciliary care, or the provision of advice and information, family support, advocacy, counselling, befriending and access to support groups. The vast majority of these services are provided to Carers free of charge. Many voluntary organisations take part in community information and support events for Carers periodically throughout the year.

Many Carers would actually prefer to approach a voluntary organisation for help rather than seek formal help from the local authority or health authority, the key feature of voluntary organisations being that they are independent. The services provided by the voluntary sector are widely regarded as being in addition and complementary to those provided by statutory organisations. There is a contact list of voluntary organisations working with Carers toward the end of this document.

Voluntary organisations are well placed to identify and respond to the ever-changing needs of Carers and are able to seek funding support from a variety of sources including the statutory authorities and other grant-making bodies. Therefore, there is considerable scope for future development of services to support Carers within the voluntary sector.

As a result of the consultation which has taken place in the development of this plan, some new developments to support Carers have already begun. Some examples are mental health befriending schemes, a Carers newsletter, development of support groups, a Young Carers' project and a network of black and minority ethnic Carers. Many voluntary organisations are very keen to diversify and expand their role in supporting Carers and are actively seeking financial support for this.

With the support provided by voluntary organisations, Carers are also enabled to have a say in shaping service provision. Cardiff Carers' Forum, in partnership with other interest groups, has a specific focus on ensuring that the Carer's voice is heard when service planning takes place. In line with a recently strengthened joint planning process and to ensure Carers have a strong voice, Cardiff Carers' Forum will change and develop over time to take on a more significant role in enhancing Carer involvement at all levels.

7. Local Authority Developments

During the process of preparing the plan, various new initiatives have already started.

Increasing Access to Leisure and Fitness

Cardiff County Council has a scheme which provides discount to various groups of people wishing to access Leisure Centres - this is called the MAX Card Scheme. Although being in receipt of Invalid Care Allowance (ICA) was already included as one of the eligibility criteria to the card, work has taken place with social and leisure services to widen access to all Carers who may not be in receipt of ICA.

Development of a Young Carers' Club

In relation to the Breaks for Carers Scheme, work is beginning within the local authority in partnership with the voluntary sector, to identify young Carers and develop a Young Carers' Club. A community venue will be used and a specific telephone line will be set up to increase access to the service.

Carers Information Pack (Pilot exercise)

Carers of the local authority service users who decline to have an assessment are receiving a pack of information pertinent to caring. The pack includes an invitation to request an assessment when the Carer is ready.

New Carers Post

In recognition of the increasing role of Carers, the authority has appointed a Policy officer with a remit specifically for Carers. This post is funded through core funds and not through the Carers' Special Grant which is being used for service development only.

Development of New Services

The local authority is developing new ways of supporting Carers under the Carers and Disabled Children's Act 2000. These services are a result of consultation with Carers and voluntary organisations in this field. Examples include new sitting and befriending services to relieve Carers of people experiencing mental health problems and emergency support for Carers.

8. Developments within Health Services

Amongst the priority areas documented in the Local Health Action Plan are Older People, Children and Mental Health. It is recognised that Carers' issues are of prime importance in each of these areas.

The NHS Plan, Improving Health in Wales: A Plan for the NHS with its Partners, and the Welsh Mental Health Strategy make specific reference to the needs of Carers. The Local Health Group and the Trust will be taking these recommendations on board wherever possible.

Carers are being invited to join various working groups associated with new health projects, such as the re-organisation of mental health services in Cardiff, the roll-out of structured counselling services and the pilot for a mental health liaison worker in west Cardiff.

Discussions are ongoing as to how to raise awareness of Carers and their needs within the Primary Care Teams.

The voluntary sector representatives on two of the Locality Steering Groups in Cardiff are associated with Carers' services and are trying to raise the profile of Carers' needs at that level.

9. Implementation, Monitoring and Evaluation of the Plan

Implementation of the Plan

The implementation of the plan will be undertaken by the Carers' Strategy Working Group (CSWG). This group comprises officers from:

- Cardiff Council
- Cardiff Local Health Group
- Cardiff & Vale NHS Trust
- Carers' Development Project
- Cardiff Carers' Centre
- and the Chair of the Cardiff Carers' Forum.

In order to implement the plan, a series of subgroups has been developed around the main themes of the plan. These are as follows:

Employment	Health
Black & Minority Ethnic Issues	Information
Young Carers	Case Management

Each of the above groups will share similar terms of reference and will be chaired by members of the CSWG. The purpose of the sub groups is to take forward the action points identified in the plan by involving other interested parties. Each sub group will report back regularly to the CSWG on progress made in each area.

Reporting Arrangements

The Carers' Strategy Working Group will report to a Management Group made up of the following officers:

- Head of Service, Families and Community Care, Cardiff County Council
- Chair of Cardiff Local Health Group
- Chief Executive: Cardiff & Vale NHS Trust
- Chair of the Cardiff Carers' Forum
- Carers' Development Project
- Operational Managers from Children's Services and Families and Community Care and other relevant officers from Cardiff Local Health Group.

Production of an annual progress report

A report will be produced each year following the launch of the plan, outlining progress made in each of the areas. This will be presented to all relevant parties including the Carers' Forum.

Appendices

I. CONSULTATION PROCESS AND PARTNERS



Consultees included:

Voluntary Sector

Age Concern, Arthritis Care, Alzheimer's Society, Crossroads, Carers' Development Project, The Catholic Children and Family Carer Society, Mental Health Development Project, NSF (National Schizophrenia Fellowship), Cardiff & Vale Parents' Federation, Cardiff Carers' Centre, Carers Cardiff Branch, Daybreak, Dementia Care Line, Let's Play To Grow, Multicultural Crossroads, Parkinson's Disease Society, Abcd (Access for Black and Minority Ethnic Children with Disabilities), Mencap, Race Equality First.

Health

Bro Taf Health Authority, Cardiff Local Health Group, Cardiff Community Health Council, Cardiff and Vale NHS Trust, Local Health Alliance, General Practitioners.

Local Authority

All Departments including: seminar attendees: Transport, Leisure and Lifelong Learning, Families and Community Care, Children's Services, Education and Human Resources.

Carers

Cardiff Carers' Forum, Ethnic Minority Carers within Greek, Bengali and Somali communities (further work to be developed), Cardiff Consultation Group (concerned with Older People with Mental Health Problems), Cardiff and Vale Mental Health Development Project and additional Carers known to the Carers' Development Project.

2. SURVEY RESULTS: CARDIFF CARERS' PLAN QUESTIONNAIRE

This document presents the summary and highlights of Carers' responses to a preliminary survey conducted by the Carers' Development Project in year 2000. The survey aimed to examine Carers' needs and serves as a valuable input in the formulation of the Cardiff Carers' Plan. The questionnaires were sent to those Carers who were unable to participate in a previous consultation meeting on this topic. A total of 120 questionnaires were distributed to Carers in Cardiff. Of this number, 37 of the questionnaires were completed and were returned for analysis.

(1) On issues which Carers think should be incorporated in the Cardiff Carers' Plan

Table 1. Issues which may be incorporated in Cardiff Carers' Plan

Issue	Percent (%)
Break for Carers	86
Information and support	81
Employment	54
Young Carers	48
Other issues	43

A break for Carers and availability of information and support were identified by the majority (i.e. 86% and 81% of Carers respectively), as key issues which should be incorporated in the Carers' Plan.

Apart from those issues identified in Table 1 above, other issues identified by Carers which may be incorporated in the Plan are the following:

- access to, and provision of, transport
- access to information concerning benefits for patients and Carers
- the provision of specialised adaptations for the home.

(2) On Carers' preferred option for a break from their caring responsibilities

Table 2. Carers' preference for break and alternative care provision

Type of break and care provision	Percent (%)
Regular weekly break with alternative care provided at home	38
Periodical short break with nursing home / hospital care provided	38
Opportunity to go away together to accommodation with appropriate facilities	35
Periodical short break with alternative care provided at home	30
Regular weekly break with alternative care away from home	27

Overall, more than one third of Carers indicated that they would value a regular break from their caring responsibilities for as long as there is available and adequate alternative care provision for the person cared for. This break from caring can either be on a regular weekly basis or can be a short periodical break. More than a third (38%) of the Carers indicated that they would like a regular weekly break with alternative care provided in their home. A similar proportion (38%) has also indicated that they would like a short break periodically, with alternative care provided in a nursing home or hospital for the person cared for.

(3) On Carers' access to, and sources of, information

Table 3. Carers' preferred sources of information

Sources of information	Percent (%)
Carers' Centre	65
Outreach services	54
Carers' helpline	51
Other sources	22

The majority of Carers (65%) indicated that they would like information on available services and support through a Carers' Centre. Their suggestions for other possible sources of information include the following: churches, the internet and a 'one stop shop' where various agencies work together to provide information using a variety of methods.

(4) On the types of support services needed

Table 4. Other types of support services needed

Services needed	Percent (%)
Participation/involvement in decision making and service planning	54
Carers' support group	54
Information on specialist services	51
Emotional support	49
General information and advice service	41
Training	27
Practical support	19

More than half of the Carers (54%) indicated that they would like to be involved in decision making and service planning. Similarly, the same number of Carers (54%) indicated the need for a Carers' support group and in particular nearly half (49%) indicated a specific need for the provision of emotional support for them, e.g. befriending services. Another type of support service needed which Carers identified concerns the provision of information. More than half (51%) of Carers indicated a need for an information service on available specialist services, while nearly half (41%) indicated a need for a general information and advice service.

(5) On access to and provision health services

Table 5. Carers' health service needs

Health related service needs	Percent (%)
Recognition of Carers' health needs	78
Health information and support	54
Practical support and training in specialised health tasks	41
Others	11

It is important to more than three quarters of Carers (78%) that their special health needs are recognised within the GP practice. More than half (54%) indicated that they would like information on health and related support services while nearly half (41%) specified a particular need for practical support and training in specialised health tasks. Other health related needs identified by a relatively small percentage of Carers (11%) relate to improvements with general NHS service provision, e.g. free dental and eye treatment, reliability and ease of Carer access to GP and social work services.

(6) On services for Young Carers

Table 6. Service needs of Young Carers

Service needs	Percent (%)
Respite and recreation/leisure opportunities	78
Mechanisms for identifying Young Carers	57
Educational help	46
Befriending service	35
Others	8

A majority (78%) indicated that respite as well as leisure/recreation opportunities should be made available for young Carers. An important issue raised by more than half (58%) of Carers concerns the need to establish ways of identifying young Carers. Other types of services identified which should be made available to young Carers are educational help (46%) and a befriending service (35%). Other needs identified by Carers (8%) are a drop-in centre for teenage Carers and training provision for young Carers which would enable them to provide better care to the person cared for.

(7) On employment support for Carers

Table 7. Carers' employment support need

Employment support needs	Percent (%)
Flexible working arrangements	51
Recognition of Carer role	49
Support networks	35
Others	5

More than half of Carers (51%) indicated the need for flexible working arrangements in their work place. In connection with the previous issue raised, nearly half (49%) of them also think that there should be a recognition of their role as Carers. Finally, more than a third (35%) suggested that a support network for Carers should be made available in the workplace. Other comments made by Carers (5%) on this issue are connected with employment policies, e.g. the right for extra leave and flexibility with regard to career opportunities for Carers.

Useful Contacts



Age Concern (Cardiff Advocacy Service)	029 2062 1111
Age Concern (Vale of Glamorgan Advocacy Service)	029 2070 4626
Alcoholics Anonymous Cardiff	029 2037 3939
Al-Anon For relatives and friends of problem drinkers	0207 403 0888
Alzheimer's Helpline Advice, information and support	0845 3000336
Alzheimer's Society (Cardiff & Vale)	029 2052 1872
Barry Citizens Advice Bureau General information and advice	01446 733 310
Benefits Enquiry Line Information on benefits	0800 882 200
British Red Cross Equipment loan centre for Cardiff	029 2023 6534
Cancer Information Service	0800 181 199
Cardiff Aids Helpline Advice, information and support	0800 0743 445
Cardiff Citizens Advice Bureau General information and advice	0870 1264 028
Cardiff Council Carers' Policy Officer	029 2087 3631
Cardiff Community Health Council Information, advocacy & advice about health services	029 2037 7407
Carers' Development Project Enabling Carers to have a voice	029 2048 5722
Cardiff Housing Help Centre Information and advice on housing issues	029 2087 1448
Cardiff & Vale Coalition of Disabled People Campaigning for equality	029 2025 5611

Cardiff & Vale Crossroads Care Attendant Scheme, Young Carers Project and Multi-Cultural Crossroads	029 2057 7300
Carers' Centre, Cardiff & The Vale Information, advice, advocacy & support for carers	029 2022 1439
Carers UK formerly the Carers' National Association Carers line and information for Carers	0808 808 7777
Carers Wales Information for carers	029 2081 1370
DayBreak Wales Developing new ways of caring which aims to offer choice to Carers	029 2022 6429
Dementia Careline Advice and information about dementia	029 2052 9848
D.I.A.L. Disability Information and advice line	01443 237 937
Disabled Living Centre Advice, sale of aids and equipment	029 2056 6281
Disability Wales Disability information line	0800 731 6282
Health Information Wales Information on self help groups	0800 665 544
Hafal (previously called The National Schizophrenia Fellowship) Advice, information and support	029 2056 5959
NCH Vale Young Carers Project	029 2070 4500
NHS Direct Wales Help Line 24 hour healthcare advice	0845 4647
Penarth & Vale Crossroads (EMI) Support for Carers of older people with mental illness	029 2070 0057
Stroke Association Information support and advice	029 2052 1728
Tenovus Cancer Information Centre	029 2019 6100
The Samaritans	029 2034 4022
Vale of Glamorgan Community Health Council Information & advice about health services	029 2051 5566
VEST Voluntary transport service	029 2048 5036