



Llywodraeth Cymru
Welsh Government

Carers Strategies (Wales) Measure 2010

Guidance issued to Local Health Boards and Local Authorities

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Carers Strategies (Wales) Measure 2010: Guidance

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SECTION 1 – PURPOSE

Within this Guidance the term ‘the Organisation’ is used to describe the lead agency responsible for developing local Information and Consultation Strategies for Carers. This will be the Local Health Board (LHB).

The term ‘the Strategy’ is used to describe the ‘Information and Consultation Strategy for Carers’.

Purpose

1.1 The purpose of the Carers Strategies (Wales) Measure 2010 was to enable the National Assembly for Wales to introduce a new requirement on the NHS and Local Authorities in Wales (the ‘Organisation(s)’) to work in partnership to prepare, publish and implement a Strategy. This Guidance is for Local Health Boards, as the lead Organisation working in partnership with Local Authorities, to enable them to implement the requirement by Welsh Ministers that they develop and put in place local Information and Consultation Strategies for Carers .

1.2 This Measure, for the first time, places a legislative duty on the NHS in relation to services for Carers in Wales.

1.3 This Guidance should be read in conjunction with the Measure itself and the Regulations. See Annex 1.

1.4 Its three Sections set out:

- the purpose and background of the Guidance;
- the format and content that a Strategy should take, including minimum requirements, a timetable for delivery and monitoring, review and evaluation arrangements;

1.5 Its two Annexes set out:

- the legislative and policy context which underpins and informs the requirement to develop a Strategy;
- Guidance interpreting ‘regular and substantial’ care which helps to underpin the legal definition of a Carer;

1.6 With the advice of the Welsh Government led Carers Measure Stakeholder Advisory Group, whose membership included representatives from Local Authorities, the NHS and the Third Sector, this draft Guidance was issued for consultation on March 31 2011 and closed on June 30 2011.

Who are Carers?

1.7 In this Measure “Carer” means an individual, whether an adult or a child, who provides or intends to provide a substantial amount of care on a regular basis for—

- (a) a child who is disabled within the meaning of Part 3 of the Children Act 1989, or
- (b) an individual aged 18 or over.

“Carer” does not include an individual who provides or intends to provide that care—

- (c) by virtue of a contract of employment or other contract with any person, or
- (d) as a volunteer for any body (whether or not incorporated)

1.8 In the Measure and in the Guidance, any reference in relation to a Carer, to ‘the person cared for’ is a reference to the person for whom the Carer provides the care or intends to provide the care.

1.9 The support a Carer provides may include but is not limited to:

- safe lifting, moving and handling;
- help with eating and drinking;
- personal hygiene;
- administering medication;
- emotional support;
- assistance with life-skills;
- acting as an advocate or guardian for the cared-for person;
- helping someone to access housing, leisure, recreation, financial and legal advice and other services of benefit;
- helping someone manage their finances; and
- use of aids and adaptations

1.10 The application of ‘regular and substantial’ is designed to ensure that only Carers with substantial caring roles have the right to a ‘Carers assessment’, as a gateway to securing practical support from the statutory agencies. ‘Regular and substantial’ has never been defined legislatively. Interpretation of ‘regular and substantial’ has been left to professionals on the ground to decide, based on the individual circumstances in each case and taking into account a wide range of factors (see Annex 2). This inevitably requires some form of preliminary screening to explore the caring role and the impact of that on the Carer.

1.11 Professional care workers and family members looking after children without disabilities or long-term health conditions are not included in the definition of Carer, as used in this Guidance.

Carer Statistics

1.12 The 2001 Census identified 340,000 Carers in Wales. This is 11.9% of the population. Out of which 13% of Carers are aged over 65. 61.1% provides care between 1-19 hours, 12.6% provide care between 20-49 hours and 26.3% provide care of 50 hours or more per week. 23.7% of Carers reported that their health was not good. The 2001 Census identified over 4,600 young Carers aged under 18 in Wales. The 2011 Census data regarding the numbers of unpaid Carers in Wales are expected towards the end of 2012. However, the ‘Care at Home’ research commissioned and published by the Care Council for Wales (see

Annex 2) reports that 96% of annual care hours in Wales are provided by unpaid carers, with the remaining 4% provided by local authorities and independent providers. Further research published in May 2011 by Carers UK (see Annex 2) estimates that the number of unpaid Carers in Wales has increased by 8% to approximately 370,000.

1.13 The 2001 Census reported 2.1 per cent - or some 62,000 people in Wales – of the Wales population coming from non-White backgrounds. The Black, Minority Ethnic (BME) population in Wales is very diverse but the group that predominates is that of Asian background (over 25,000 or some 40 per cent of the total BME population). However, these figures do not represent the current increase in the numbers of people coming from Eastern European countries. In considering the BME Carer population, reference should be made to the WAG Guidance *They Look After their Own* (see Annex 1)

Demographic Trends

1.14 There is a move both, nationally and locally, away from acute services and more focus on community support. This, in turn, could potentially put more pressure on Carers. Research has found that due to people living longer and women having children later, the so-called “sandwich generation” — women who have to deal with the competing demands of holding down a job and caring for both children and ageing parents — is growing.

Impact of Caring

1.15 There is growing evidence that caring can have a detrimental impact on the physical, emotional and mental health of Carers and that their health is increasingly at risk as their caring responsibilities increase. Carers in Wales providing high levels of care are a Third more likely to suffer ill health than non-Carers: 23.7% of Carers in Wales reported their health wasn't good in the 2001 Census. Young Carers are twice as likely as their peers to have mental health issues and BME Carers are often described as an isolated community within an isolated community. When a caring relationship breaks down (often because unsupported Carers can no longer cope), it can result in the admission of the cared-for person, the Carer, or both, to hospital or local authority care. This is particularly an issue where older Carers are caring for spouses, partners or friends or adult children with learning disabilities. Many parent Carers of children with complex needs and challenging behaviours face high levels of stress over a long period. Without additional support, severe strain is often placed on the wider family, impacting on the development of other siblings. Often children with complex needs are looked after by a single parent, as a result of a marital or partnership breakdown.

1.16 Research and recent policy developments acknowledge the occupational hazards of caring, particularly for those family Carers providing over 20 hours of care a week. Unpaid Carers, like paid care staff, require support to fulfil their roles, such as information, training, financial and emotional support, equipment and adaptations and breaks from caring. The need to support Carers was recognised by the Welsh Government in 2000 through the publication of its Carers Strategy (see Annex 1). Providing Carers with appropriate information and support early in their caring role requires early identification, particularly through local health agencies.

1.17 Maintaining the health of Wales' unpaid care force therefore requires a health service which identifies Carers and their health needs early, and pro-actively supports Carers to look after their own physical and mental health needs. This support needs to be through a wide

range of health checks and preventative programmes, information on dietary health, signposting and referral to appropriate agencies who can offer peer and emotional support as well as support Carers to access leisure opportunities and breaks from caring. The impact of caring on the health of young Carers and Carers from BME communities requires specific consideration to ensure appropriate health-promoting initiatives which are sensitive to age, culture and family circumstances.

SECTION 2 – POLICY CONTEXT

Aims and Objectives

2.1 Carers are a key partner in the delivery of care and supporting their involvement is central to the sustainability of care provision. Supporting Carers is a key element of the Welsh Government's health and social care agenda. It is also in line with the Welsh Government's priorities of social inclusion, reducing health inequalities and building better communities. The Welsh Government has restated its commitment to Carers in the Labour Manifesto and in the Paper on Sustainable Social Services for Wales: A Framework for Action.

2.2 The unpaid care workforce is the single largest provider of care to people with support needs in our communities. It is also known that there is a sizeable gap between policy and delivery of support, which will be addressed through the full and proper implementation of this Measure.

2.3 *The Paper on Sustainable Social Services for Wales: A Framework for Action, and Together for Health* (see Annex 1) recognise the role of Carers in supporting the health and welfare of those they care for. In addition to providing health care, Carers help to promote independence, prevent or delay admissions to hospital or care homes and facilitate early and effective discharge from hospital.

2.5 The Welsh Government's vision for Carers is to:

Facilitate early identification of Carers by the Organisation(s). Thereby improving access by Carers to the information and services that they need to help them to care, in order to protect their own mental and physical health. This needs to be done across adult and children's services.

Ensure that Carers receive earlier and more planned support, through local partnerships or joint commissioning involving the NHS, local authorities, the Third sector and the private sector.

Create cultural change so that Carers are empowered in the decision making processes around care management and at a strategic level in service planning and delivery.

Ensure that Carers' issues are mainstreamed into the everyday working practices of NHS and other staff, to ensure that staff work with Carers in effective partnership both to support the Carer but also to maximise patient/user care.

A list of Key Legislation, Strategy and Policy can be found at Annex 1.

SECTION 3 – FORMAT AND CONTENT

3.1 This Section of the Guidance sets out a series of minimum requirements of a joint Strategy. This Section also gives the timescale for submitting Strategies to the Welsh Government and details the monitoring arrangements that the Organisation(s) must follow.

NHS Role in Supporting Carers

3.2 The vital role of the NHS in identifying Carers, offering them information and signposting or referring them to sources of advice and support is widely documented in research, publications and current NHS policy drivers. Research shows that for 4 out of 5 Carers, their first point of contact with any statutory agency is with a community-based health service. Research also shows that this first point of contact is generally within a primary care setting, either at a health centre, GP practice or at home. Identifying all Carers and providing them with information at the earliest point of contact is central to the aim of creating effective Information and Consultation Strategies for Carers. **Information provision is not a one-off exercise, however. It will usually need to be an ongoing process.** The primary purpose of the Strategy is to ensure that Carers receive appropriate information systematically to give practical effect to the requirement on the NHS to work with Carers as key partners in the care management process and particularly at key stages of the patient/Carer journey. The Ministerial power to require the development of Information and Consultation Strategies for Carers seeks to deliver systematic Carer identification and provision of information to Carers, based on existing good practice.

Local Authority Role in Supporting Carers

3.3 Local authorities have long had responsibility for meeting Carers needs and the work has invariably been led by Social Services Departments. Education Departments have a role to play in relation to young Carers and Housing Departments also have a role to play for all carers. The Carers (Recognition and Services) Act 1995, the Carers and Disabled Children's Act 2000, the Community Care (Delayed Discharges) Act 2000 and the Carers (Equal Opportunities) Act 2004 are examples of the legislation that require Local Authorities to carry out certain functions in relation to Carers, for example, to carry out Carers needs assessments to determine suitability for support. Various pieces of Welsh Government guidance flow from these Acts (see Annex 1) and in many local authorities, there are elected Members who are Carers Champions.

3.4 **The duties placed on Organisations via this Measure do not replace those already in place for local authorities. Rather, they consolidate and complement them.** This Guidance also reminds Organisations that the Carers and Disabled Children Act 2000 provides for Local Health Boards to undertake Carers needs assessments. Given the duties placed on the NHS via this Measure, Local Authorities may wish to use the opportunity offered by this Act to make robust arrangements with their partner LHBs to carry out these assessments.

Joint Working and Strategy Development

3.5 Organisations are expected to lead the development and maintenance of an effective Strategy. This will require significant and sustained organisational and management development with successful leadership. It will be critical to ensure that there is effective leadership at all levels, but particularly at a senior level in the Board, to ensure that staff are

appropriately trained and aware of the requirement to identify Carers, to provide Carers with targeted information, to advise Carers of their potential right to a needs assessment and, to adopt the good practice of signposting Carers on to appropriate sources of advice and support.

3.6 The Strategy must be developed and operate in an environment based on partnership-working, team-working, information-sharing and service integration across all levels of the NHS. It must function in partnership with Carers, patients, NHS staff, local authorities, the Third sector, the private sector and other relevant groups. Such partnership working is not new. A Strategy must be built upon the existing partnerships and working practices already created through the implementation of, for example, Health, Social Care and Wellbeing Plans and Children and Young People's Plans. The success of an effective Strategy will depend greatly on the quality of these partnerships as well as effective communication and joint-working between all partners, including Carers and the Third sector. It will also depend on open and robust accountability within statutory and independent agencies.

3.7 Information and Consultation Strategies for Carers should sit alongside local Carer strategies, which have generally been developed by local authorities. As well as providing the development framework for services to support Carers, local Carer strategies generally address issues such as Carer identification and the provision of targeted information to Carers.

3.8 Strategies should also cover how information for out of area patients is provided. For example, Organisation areas such as Cardiff and Vale Local Health Board provide specialist services to a number of patients from outside the area and will need to consider the provision of information to assist Carers from the home areas where patients live.

3.9 Strategies should also make linkages with the work of Local Safeguarding Children's Boards, so that young Carers who appear to NHS staff to be vulnerable or at risk for any reason, but especially because of their caring role, are identified by NHS staff and the appropriate agencies brought together to assist as required. NHS staff should be aware that many young Carers exist in family situations where there is substance misuse or where a parent has mental health issues. In all matters the welfare of the child is paramount, especially when there are conflicts of interest. Young carers would also benefit from Strategies making links with local Education services. Information can be provided by teachers, teaching support staff, Education Welfare Officers as well as school counsellors and school nurses.

3.10 As a minimum a Strategy must:

demonstrate how the Organisation has identified, in discussion with Carers, Carer organisations, the wider Third sector and local authority partners:

- the information Carers need;
- how it will be provided; and
- by which lead agency.

ensure that NHS staff as a minimum are able to signpost Carers that they come across on their day to day duties to a local Carer support agency and, if patient confidentiality allows, to appropriate national organisations supporting patients, users and Carers for specific conditions. For example: Carers Wales, the Princess Royal Trust for Carers,

Crossroads Care, Alzheimer's Society Wales, Macmillan Cancer Support, Parkinson's Disease Society, Hafal and Contact A Family. This is not an exhaustive list.

This Guidance makes a best practice recommendation that where a Carer appears to the Organisation to have a significant caring role, staff formally refer such Carers on to appropriate sources of support, i.e. local Carer support agencies.

3.11 The Strategy should set itself in context with other policies by including:

- a description of how the Strategy sits alongside other key policies such the local Health, Social Care and Wellbeing Strategy;

- a description of how the Strategy sits alongside existing local Carers strategies;

- a description of the mechanisms in place that would initiate joint action with partner agencies when the Strategy identifies young Carers who may appear to NHS staff to be at risk or a 'child in need' because of their caring role, or other associated factors;

- a description of how local joint agreements on issues of consent have been reviewed in order to ensure that they adopt the principles set out in the Information and Consultation Strategy for Carers and facilitate the proactive provision of information to Carers;

- a description of how the Strategy ensures that it supports equality responsibilities, for example, the requirement to implement Race Equality Schemes

Engaging Carers, Partners and Communities

3.12 The Strategy should be developed using a bottom-up approach in partnership with key stakeholders. Organisations have legal responsibility for implementing this Guidance and therefore for developing the Strategy. In doing so Organisations should maintain an effective, formal dialogue with local Carers, Carer organisations and the wider Third sector to ensure that the Strategy is fully developed, working effectively and providing Carers with the information they need. This reflects the existing duty on Organisations to involve and consult the public on service delivery and the wider public involvement agenda which aims to make public services more responsive and accountable to citizens and local communities. Organisations should report to their local communities, through existing networks of patient/user and Carer groups and community care forums, on how their views are taken into account in the development of a Strategy. Organisations would also benefit from identifying and engaging with new Carers

3.13 A Strategy should be tied in to the wider range of public involvement structures and processes already in place to ensure community engagement in care management and service planning. These provide a good opportunity for those working in the health arena to discuss with local partners, including the Third sector, how best to streamline and improve local involvement processes, building on good practice and joining up activity wherever possible.

Scope of Information and Consultation Strategies for Carers

3.14 The Strategy will provide for the provision of information and advice to Carers and for the effective involvement of the relevant authorities with Carers when making decisions about the

provision of services to or for Carers or the person cared for.

3.15 It is recognised that Carers who are given information on their rights and on avenues of support early on in their caring role feel better equipped to cope with the pressures of caring, even if they do not have or invoke those rights until later. In order to create a preventative approach in line with the *Paper on Sustainable Social Services in Wales: A Framework for Action* and *Together for Health* (see Annex 1) and in order to minimise the requirement on NHS staff to assess whether a caring role is regular and substantial, this Guidance suggests that the Organisation(s) extend their Strategy to all Carers that they come across in their day to day duties, in particular the provision of information to help support the Carer in their caring role, advising Carers of their potential right to a Carers needs assessment and signposting Carers on to sources of support and advice.

3.16 The scope of this Guidance might appear to go beyond the provision of information by requiring training of Organisation staff on Carer awareness. However, staff development and training on Carer-related issues is fundamental to ensuring that information provision is mainstreamed into the day to day activities of NHS professionals and staff at all levels. The Guidance also requires Organisations to meet, with local partners, the training needs of Carers. Staff development and training is viewed as a means of providing valuable information that will support Carers in their caring role.

3.17 Where a Carer appears to an Organisation to have a significant caring role, best practice would involve NHS staff formally referring such Carers on to appropriate sources of support, i.e. local Carer support agencies. An example of a health organisation providing information to Carers are GPs. 97% of GP practices in Wales, have Carer identification and referral protocols in place under the GMS contract Quality and Outcomes Framework, Practice Management Indicator 9.

Objectives of Information and Consultation Strategies for Carers

3.18 The purpose of a Strategy is to ensure the Organisation(s) create a strategic framework within which the objectives set out below will be delivered. Welsh Ministers expect a Strategy to clearly demonstrate how these objectives will be met and monitored. How this is achieved is set out in the Regulations which inform this Guidance. **The Regulations set a baseline of requirements but it is the responsibility of Organisations to undertake further work depending on the needs that Carers indicate to them.**

3.19 The overall objectives of a Strategy are to ensure that Organisations work in partnership with Carers, patients, local authorities, the Third sector, the private sector and other relevant groups to ensure:

- the identification of Carers by staff and professionals at all levels within the NHS;
- and

- the effective provision of relevant, up to date and targeted information to Carers at every point of their journey through the NHS. Information provision is an ongoing process throughout the patient/Carer journey and information should be provided at key stages. These will include hospital admission, diagnosis, transfers of care, the start of treatment programmes and significant changes to treatment or medication, hospital discharge/other transfer of care and out of hours support.

- Carers are informed of their legislative right to an independent assessment of their

needs as a Carer;

patient consent is sought as a first step, where appropriate, as a basis for providing information to Carers and where tension arises between the needs of Carers and patients, mediation is fully explored;

that where consent is withheld, Carers are provided with as much information as can be shared without breaching patient confidentiality, including information on:

- medication, where the Carer is required to dispense medication;
- treatment, particularly in relation to side-effects on the health and behaviour of the person cared for that may impact on the Carer;
- the provision of advocacy services; and
- practical issues relating to care at home and long-term care.

that where patients are unable to consent through incapacity, practitioners work with partners and/or immediate family, sharing information as appropriate so that full consideration can be given to possible action under the Mental Capacity Act 2005.

that the Strategy dovetails with the requirements of all relevant statutory plans

that the Strategy deals with the requirements around care and treatment planning under Part 2 of the Mental Health (Wales) Measure 2010

that NHS staff as a minimum are able to signpost Carers that they come across on their day to day duties to a local Carer support agency and to appropriate national organisations supporting patients, users and Carers for specific conditions. For example: Carers Wales, Crossroads, the Princess Royal Trust for Carers, Alzheimer's Society Cymru, Macmillan Cancer Support, Parkinson's Disease Society, Hafal and Contact A Family. This is not an exhaustive list.

that the Strategy recognises that Carers are not one homogenous group but have specific, individual needs;

that Carer awareness is mainstreamed as part of the day-to-day activities of NHS staff at all levels, whether employed by or contracted to the NHS;

that clear, measurable outcomes are delivered for Carers in terms of being better informed of how to access appropriate support as a result of targeted NHS information.

General Principles of Information and Consultation Strategies for Carers

3.20 A Strategy should adopt the following fundamental general principles in terms of its development and implementation:

It must never be assumed that carers can or will provide care. Carers can choose whether or not they will care and the level of support they are prepared to offer. The amount of caring they can and are willing to provide must be negotiated and regularly reviewed.

Make a statement of principle recognising and treating Carers as key partners in the provision of care. These statements should reflect the different position of young Carers who must be engaged and consulted with, particularly in terms of developing the Strategy;

When providing this information, relevant authorities should engage with carers to ensure that they understand their level of knowledge of the condition of the individual being cared for. **‘Engaging’ means not only providing written information to carers but also talking to them.** The principle should be that where some one is identified as a key person in the care plan ascribed to an individual they are provided with all the information and advice they need to carry out their caring role effectively;

Make a statement of commitment that all levels of the NHS will work in partnership with Carers and that this is reported upon;

Make a statement which recognises the statutory duty to inform Carers of their right to a needs assessment via the Carers Recognition and Services Act 1995 and the Carers and Disabled Children’s Act 2000;

a principle of accessibility, ensuring that information and advice is widely available and available in a variety of different formats to meet the varying needs of carers. This should include information being made available face to face, in hard copy, in other languages including Welsh, in non-written forms such as DVD and video, in Braille, in audio, in large print, in a range of locations such as GP surgeries, pharmacies, community centres, places of worship, schools and colleges, online formally on organisational websites and informally on social networking websites etc.

a principle of consultation, ensuring that Carers are fully involved in all decisions relating to the care of the cared for person

a statement of commitment to ensuring that information and support is available and accessible to Carers of all ages and all sections of the community, i.e. Carers from BME communities, as required under the Race Relations (Amendment) Act 2000; and

a statement of commitment to the principles of equality and diversity.

Content of Information and Consultation Strategies for Carers

3.21 The Organisation, working in partnership with Carers, patients, local authorities, the Third sector, the private sector and other relevant groups, will be expected to demonstrate, as a minimum requirement, within their Strategy, how they will deliver the minimum requirements set out within this Section of the Guidance. They should also demonstrate how the Strategy will deliver the overall objectives and principles listed above. The following paragraphs make explicit the need for NHS and Social Services action in key areas of service delivery. They also set out requirements for action in areas such as training, accountability and involvement.

3.22 The Deputy Minister for Children and Social Services further requires that all local Strategies contain a Chapter that focuses on meeting the information and consultation needs of young carers. This Chapter will need to respond to the specific needs of young carers following the suggested content outlined below. A child becomes a ‘young carer’ when the level of care-giving and responsibility to the person in need of

care becomes inappropriate for that child and impacts on his or her own emotional or physical well-being or educational achievement and life chances (see Annex 1).

Information - Suggested Content

3.23 As stated in the Regulations, the following areas of information and support should be considered and provided to Carers as appropriate, making sure that full account is taken of their age, language requirements, cultural requirements, disability and any other specific need. This list provides examples of the kind of information Carers will find useful: it is intended to be a baseline to build upon. The information required by Carers will vary on a case by case basis:

information for Carers of people with mental health problems on their specific legislative rights (see Annex 1);

information about the medication given to an individual and where appropriate the potential side effects;

general or specific information on medical condition/treatment in accordance with patient confidentiality, the conditions and treatment of the cared for person, including information on side effects of treatment (even if confidentiality precludes disclosure of diagnosis);

information that assists children and young people to avoid taking on inappropriate levels of caring and signposts them to sources of assistance;

accessible information and signposting to information on the availability, entitlement to and sources of local and national support including:

- short breaks / respite care
- Carers Needs Assessments
- Direct Payments
- housing support
- independent advocacy
- counselling including bereavement support
- guardianship if appropriate
- the work of the Court of Protection if appropriate
- age appropriate support groups
- culturally specific support groups
- financial advice and support, including information about the availability of financial support through the benefits and tax credits system
- managing the financial and other affairs of cared for persons
- any other information and support available to help support Carers in their caring role

information, or signposting to information and advice, on employment provisions, including flexible working

information on:

- the range of Social Services functions available to Carers and cared-for persons
- care planning for the person cared for
- medicines management, safe handling, moving and lifting and other matters relating to the care of the person cared for

inform Carers of local concessionary or other transport schemes and patient transport arrangements, to enable them to attend NHS appointments with the cared for person;

information and support on aids and adaptations including Telecare and Telehealth services and the waiting times one can expect for such items;

information on the regulation and inspection of services, i.e. the work of Healthcare Inspectorate Wales and the Care and Social Services Inspectorate for Wales; signpost Carers on to a local carer support agency and to appropriate national Organisations supporting patients, users and Carers for specific conditions; information on hospital admission avoidance; information, advice and support on the availability of suitable local services, the quality and range of provision and how to choose and arrange provision of these services; information on the availability of crisis support and how to access it; information on the availability of re-ablement and intermediate care; help promote health and wellbeing for the carer and person(s) cared for (e.g. including information and training on stress management techniques, healthy diets and physical exercise); information on the Organisation's complaints procedures and those of the Public Service Ombudsman for Wales; information for carers who wish to stop their caring role; and signposting to appropriate programmes of support and learning, these may include training on:

- > safe lifting, moving and handling
- > medicines management including the safe administration of medication to the cared for person
- > relevant nursing skills
- > use of aids and adaptations
- > continence care
- > stress management
- > help with eating and drinking
- > dealing with the behavioural aspects of the cared for person
- > helping Carers to look after themselves

Information on hospital discharge and transfers of care should include as a minimum:

information about the support and follow up available on discharge for the carer and the patient; including the practicalities of the process, timing, medication rights to assessment etc;

personal and often sensitive information relating to the individual patient about the diagnosis, prognosis and treatment and management both in hospital and afterwards; and information that enables the Carers to perform their future role safely and with the necessary skills and knowledge to make informed choices about capacity to meet the needs of the patient who becomes the person cared for both on discharge and over time.

This information needs to be provided to assist the carer to decide if they want to be a carer and to enable them to choose the level of responsibility they wish to take.

Carers should also be involved in the development of information resources.

This Guidance makes a best practice recommendation that Organisations should have Carers information packs and these should be made available to all carers as a matter of course. Carers information packs should be made available on hospital wards, in GP surgeries and for community health staff (health visitors, physiotherapists etc) to take with them on home visits. LHBs and local authorities will need to work together to demonstrate how these will be reviewed and updated to ensure information remains current.

Communication and Consultation – Suggested Content

3.24 Communication and consultation with carers should involve them as partners and Organisations should consider the following issues when speaking with them:

- that Carers are consulted in a timely manner **before** a decision is made;
- that Carers are provided with an explanation of decisions made in their absence;
- that Carers are made to feel valued as partners in the consultation process;
- that the knowledge that Carers have about caring for the cared for person will be used appropriately;
- that Carers are aware of their right to have their needs identified;
- that Carers feel confident of continued support in their caring role and to get support before it becomes a problem;
- that Carers have the right information and advice on which to understand the decisions being made and be able to input into them; and
- that Carers understand the information being provided and consulted on, what will happen and who to contact.

This Guidance makes a best practice recommendation that with Carers' consent, Organisations including GPs should request to see a copy of Carers needs assessments. This will help staff to better meet the information, communication and consultation needs of Carers.

3.25 The Strategy should detail how the Organisation will ensure the participation of Carers before making decisions of a general nature, regarding the provision of services to or for Carers and the persons they care for. When doing so this consultation must, as a minimum:

- engage individuals (such as family members, advocates, individuals granted Enduring or Lasting Power of Attorney under the Mental Capacity Act and court appointed deputies) as early as possible;
- provide feedback to those consulted, explaining what action has or has not been taken and why. It must also be proportionate to the issue(s) being consulted on;
- act on the information received;
- be ongoing. Carers state that having someone to explain and revisit options perhaps on several occasions, is often needed;
- allow sufficient time for responses and for that time to be proportionate to the issue being consulted on;
- be culturally appropriate;
- be age appropriate;
- be available through a variety of methods and include both written information and information in other media, such as stakeholder meetings. It is important to ask Carers how they wish to be involved;
- consult Third sector Organisations, care providers, Carers and service users; and
- take steps to ensure that staff responsible for this consultation are trained to effectively consult with Carers.

3.26 While it will be for those drawing up each Strategy to establish with the participation of Carers what its priorities should be, we would envisage that these include:

training for each Organisation's own staff, such as Nurse Ward Managers, District Nurses, Health Visitors, Paediatricians, Social Workers and Social Care Workers on their role in successfully delivering the Strategy;

the involvement of GPs and surgery staff on their role in successfully delivering the Strategy

the expansion of the existing Carers co-ordinators role within each local authority Social Services Department or the appointment of new co-ordinators to embrace other local authority service areas, for example, Housing;

where necessary, providing funding to develop and sustain a local Carers infrastructure or strengthening any existing Carers infrastructure for authorities to effectively engage with;

meeting the reasonable engagement costs of Carers and Carers Organisations, for example travel and subsistence costs and replacement care costs;

the establishment of local information and advice services;

funding an increase in the community based capacity of Carers Organisations to help and support Carers;

the funding of Carers training 'partnerships' and delivering training to Carers themselves;

and

the development of new information and advice materials for Carers in a range of accessible formats and languages

The Strategy should detail the funding that has been provided to develop and sustain a local all-ages Carers infrastructure or to strengthening existing all-ages Carers infrastructure to allow the Organisation to effectively engage with Carers. There also needs to be mechanisms in place for front line staff to report back to senior staff to inform them about what they are learning from Carers.

3.27 Additionally, this consultation must include as a minimum:

specified arrangements for the involvement of Carers of all ages and carer Organisations, Organisations representing Carers from groups who need to be consulted in ways other than standard forms, local authorities and other key stakeholders in developing and reviewing the Strategy. In relation to Carers, Organisations must ensure they provide sufficient advance notice to enable carer involvement and offer reimbursement of travel and subsistence costs and replacement care costs;

set out how the Organisation have worked work in partnership with Carers, local authorities, the Third sector, the private sector and other relevant groups to agree indicators/outcomes and monitoring systems.

SECTION 4: DELIVERY

Delivery of Information and Consultation Strategies for Carers

4.1 The NHS in Wales has been reorganised into seven Local Health Board areas and they have been working with the 22 Local Authorities to reform service planning structures. As mentioned earlier in this document, there is now a greater focus on shifting the balance of care away from acute settings into the community. The Welsh Government document *Setting the Direction* (see Annex 1) supports this shift. Organisations should ensure that the **LHB Chief Executive and the Director of Social Services** is invested with the responsibility of ensuring that all staff in that operational sphere are appropriately informed, trained and equipped to support Carers as detailed in the Organisation's Strategy. Frontline service managers in particular have a crucial role to play in this area.

4.2 As a minimum a Strategy must:

- describe the practical steps which will be taken to deliver the Strategy objectives systematically throughout the Organisation's area;

- describe how the Organisation's joint arrangements with local authorities, the Third sector and private sector will support the objectives of the Strategy;

- develop strategic proposals to address the identification and information needs of specific Carer groups such as young Carers and Carers from BME communities; recognise that the *method* of information dissemination and consultation is as important as its format and content. Therefore proposals will need to include *how* information will be disseminated and *how* consultation with carers will take place.

This Guidance makes a best practice recommendation that each lead and partner Organisation for a Strategy must make a hard copy available for reading, free of charge, at all reasonable hours at the central and any local offices of the Organisation. It should also publish its Strategy on the Organisational website(s). In order that the Strategy is a living, effective document that achieves real change in the relationships between carers and the NHS, the Strategy needs to be disseminated to all staff groups, in all settings, including Community Health Services. It must be readily available for reference by all staff members, regardless of their status and in an easily accessible format. Staff should be made aware that there are expectations on them to contribute to the delivery of the Strategy and they should be reminded of this in regular supervision sessions, circulars and so on and regular monitoring should be set up on a departmental basis.

Strategies should also be published on the websites of the Welsh Government, NHS Wales, the Social Services Improvement Agency (SSIA), the National Leadership and Innovation Agency for Healthcare (NLIAH), the Commissioner for Older People and the Children's Commissioner.

Community Health and Social Care Services

4.3 A wide range of health services have a crucial role to play in ensuring that Carers are identified and provided with information at first point of contact. Where professionals/staff are independently contracted, Organisations should take a proactive role regarding Carer identification, information and signposting amongst such professionals/staff and should

explain within the Strategy how this is being taken forward. Key community-based services include:

- GP Practices/Primary Care Teams (see Regulation 5(1)(a);
- hospital and community-based pharmacists;
- community hospitals including those for the Elderly and Mentally Infirm;
- community assessment and rehabilitation/re-ablement;
- out patient clinics, particularly those dealing with chronic disease management;
- psychiatrists and mental health clinics;
- dieticians;
- occupational therapists
- podiatrists;
- community child health services;
- community health projects funded by LHBs;
- school nursing and school counselling

4.4 The Strategy should also apply to NHS staff working in partnership with services delivered by local authorities, as well as the Third and private sectors in community-based health/social care services. Such services include:

- council home care/day care/housing services/leisure services;
- private sector home care/day care services
- older people's services;
- children's services;
- community mental health services (including psychology);
- Learning Disability services;
- acquired brain injury services;
- services for people with physical/sensory disabilities;
- rapid response teams;
- drug and alcohol services;
- other social work and social care services and
- health practitioners working with education authorities such as school nurses.

4.5 As a minimum a Strategy must:

- demonstrate how Organisations are promoting Carer identification and the provision of targeted information to Carers by the services listed above. In relation to GPs and Primary Care staff, this should demonstrate the link between practice involvement and the GMS contract Quality and Outcomes Framework, Practice

Management Indicator 9 involving Carer identification and referral.

This Guidance makes a best practice recommendation that Carer Champions are identified within GP surgeries, hospital wards and clinics and act as a source of information for Carers and that a non-officer member of each LHB Board is nominated as a Carers Champion.

Acute/Hospital Services

4.6 Each hospital directorate/service should be able to fulfil the requirements set out in this Guidance. A Carer's first contact with the statutory agencies could be in any of a hospital's departments/directorates. Senior Managers and frontline clinical managers should be identified in all sectors, including acute services, to implement the Strategy in their area of responsibility

4.7 The Welsh Government Hospital Discharge Planning Guidance 2005 (see Annex 1) already requires the full involvement, at all times, of patient and Carers in decisions about an individual's care. In the case of planned admissions, discharge planning should be initiated prior to admission. This Guidance already requires hospital teams to have protocols for involving patients, relatives and Carers.

4.8 As a minimum a Strategy must:

demonstrate how hospital staff ensure that Carers are routinely identified and given targeted information and how staff ensure that Carers are signposted to appropriate support services and made aware of their potential right to an assessment;

set out how Carer identification, the provision of targeted information to Carers, Carer signposting on to sources of advice and support, and advising Carers of their potential right to an assessment is integrated into hospital admission and discharge procedures and admission procedures.

Training and Development for Health and Social Care Staff

4.9 Organisations will need to ensure that staff have the appropriate training to deliver the Strategy (see Regulation 5(1)(b)). LHBs should build on successful local partnership-working so that frontline staff and professionals are trained in Carer awareness issues and are supported to deliver the Strategy.

4.10 Training is already happening in some core curriculum for social work and health graduates/trainees. The Welsh Government will seek to ensure that this is systematic and widespread by improving Carer-awareness training in all graduate training curriculums for health and social care professionals.

4.11 Training and development of existing NHS employees, who have had no Carer awareness training, should happen in a range of ways, including induction, joint training and, on-going education and communication in relation to health and social care. **Joint learning opportunities should be promoted, where practical, to increase the awareness of Carers' issues within the NHS and also with local authorities, Third sector organisations and the private sector (where appropriate).** The contribution of the Third sector in training provision should be taken into account when developing awareness-raising

and training programmes. The knowledge, expertise and experience that many Third sector organisations have in relation to carers will add significant value to staff training. Carers themselves should also be involved

4.12 The training and development of key staff should be prioritised so as to achieve the greatest benefit for Carers and the Strategy should set out clearly what progress will be delivered within the Strategy's lifetime.

4.13 Training and development should be mainstreamed as far as possible into existing training modules, for example Hospital Discharge, UAP and Child Protection training which could provide a vehicle for addressing young Carers' issues. Training on Carers' issues, should be sufficiently robust to cover the issues in a meaningful and effective way and to enable staff to recognise Carers with substantial caring responsibilities, so that they can be signposted or formally referred to sources of advice and support. Training should also make links to protection issues both for vulnerable adults and children in recognition that some caring relationships are abusive. Training mechanisms should be agreed locally and set out clearly in the Strategy.

4.14 In recognition of the need for professionals in the mental health field to work in partnership with Carers as key partners, the Royal College of Psychiatrists has already agreed to prepare a code of conduct for professionals on issues relating to Carers. From 2005, the College has required post-graduate accreditation to have a Carer awareness component in the curriculum, with Carer-led training.

4.15 As a minimum a Strategy must:

- include detailed action plans for the training of staff over the lifetime of the Strategy, outlining how Carer awareness, Carer identification, the provision of information to Carers, advising Carers of their right to a needs assessment, Carer signposting to sources of advice and support and working with Carers as key partners are being mainstreamed into NHS practice; specifically through induction programmes, pre-qualification professional training, continuous personnel development and professional training and leadership development;

- set priorities for staff training in agreement with local partners, including Carers and Carer organisations, Local Authorities and Third sector organisations;

- include in action plans details on training for staff on specific issues facing, for example, young Carers, Carers from BME communities and Carers of people with dementia, mental health problems, physical disabilities, sensory disabilities, Learning Disabilities and so on

Training for Carers

4.16 Compelling evidence demonstrates the considerable benefits that can be achieved for patients, Carers and the NHS by training and supporting family Carers. Improved Carer support is cost effective in a range of ways, enabling patients, particularly those with chronic long-term conditions, to be supported longer within the community, and for older people delaying residential care. Better supported Carers, particularly those with intensive caring responsibilities are also much less likely to present at GPs with their own health issues.

4.17 As a minimum a Strategy must:

identify proposals for the development of a strategic approach to 'expert Carer' training, aimed directly at supporting Carers in their caring role and targeted specifically at Carers with intensive, or potentially growing, caring responsibilities;

identify in partnership with Local Authorities and local Carer support agencies what training already exists for Carers and how this will be developed and extended over the lifetime of the Strategy;

demonstrate delivery of person-centred training for Carers, covering advice on physical and emotional well-being including demonstrations on safe lifting, moving and handling techniques, the use of aids and adaptations, stress management, advice on medicines management including its safe administration, advice on specific conditions such as caring for someone with dementia, mental health problems, physical disabilities, sensory disabilities, Learning Disabilities and so on;

set priorities for Carer training in agreement with local partners, including Carers, local Carer support agencies and local authority partners. In doing so local training partners should explore the role of further education establishments and existing Carer training packages for example Mental Health First Aid, as well as the delivery of training using IT systems and technology.

SECTION 5: REVIEWING, MONITORING AND SUBMISSION

Reviewing Information and Consultation Strategies for Carers

5.1 As a minimum, a Strategy for Carers must:

specify the arrangements for the involvement of Carers, family members, advocates, Carer organisations, individuals granted Enduring or Lasting Power of Attorney under the Mental Capacity Act, court appointed deputies, local authorities, Third Sector organisations and other key stakeholders in reviewing the Strategy;

specify arrangements for involving young Carers, through local organisations/bodies representing young Carers including schools and colleges, in reviewing the Strategy;

specify arrangements for the involvement of Carers from groups who need to be involved in ways other than standard approaches in reviewing the Strategy.

5.2 Annual reports must also be prepared and submitted to Welsh Ministers on how the Organisation is implementing and evaluating their Strategy and setting out progress.

Monitoring Information and Consultation Strategies for Carers

5.3 This Guidance seeks to ensure that a focus on outcomes for Carers is built into each Strategy, particularly through the systematic development and implementation of baseline information, performance indicators and meaningful qualitative data against which quality improvements for Carers can be measured.

5.4 Organisations must take lead responsibility for monitoring, effectively and regularly, the outcomes achieved for Carers in terms of their Strategy and the requirements of that Strategy, as set out in this Guidance. To do so effectively, Organisations will want to work in partnership with Carers, patients, NHS staff, local authorities, the Third sector, the private sector and other relevant groups. Local authorities have similar legal duties placed on them to identify Carers and to advise them of their right to a needs assessment. Local Authorities must also be able to demonstrate compliance with this duty.

5.5 They should also set out how monitoring arrangements fit in with accountability for other areas, for example, the NHS Annual Quality Framework, the Annual Council Reporting Framework for Social Services, Hospital Discharge and Transfers of Care arrangements, the Health, Social Care and Wellbeing Plans and the Children and Young People's Plans.

5.6 Work will be taken forward to develop a National Outcomes Framework to gauge the implementation of the Measure in terms of the benefits realised for Carers. This will be led nationally by the WLGA and NHS service leads in association with the All Wales Carers Officers Learning and Improvement Network. The Framework will build upon the Annual Quality Framework for the NHS and Service Improvement Data Sets for Local Authorities.

Submission of Information and Consultation Strategies for Carers

5.7 **Nine Local Information and Consultation Strategies are required: one for each of the seven LHB areas and their partner Social Services departments plus a Strategy each**

from the Welsh Ambulance Service and Velindre NHS Trust.

5.8 Organisations are required to formally submit their Strategy to Welsh Ministers for approval by **31 October 2012. Ministers will respond to Organisations to inform them of their approval or rejection within 8 weeks.** Strategies should:

- be developed jointly with partners
- cover a three year period and address all the minimum requirements set out within the Regulations and Guidance produced by the Welsh Government;
- cover the whole of the Organisation(s) area of responsibility;
- align to existing planning and monitoring cycles, for example those in place for Health, Social Care and Wellbeing Strategies, Children and Young People's Plans and the Annual Council Reporting Framework for Social Services; and

5.9 If a Strategy is rejected because there is insufficient detail or an Organisation has failed to meet the requirements set out in the Guidance, the document will be returned to the Organisation with a requirement to resubmit it within a timescale specified by Welsh Ministers.

5.10 If an Organisation wishes to substantially alter the nature of its Strategy, a revised document will require Ministerial approval.

Annex 1 – Key Legislation, Strategy and Policy

Although this is not an exhaustive list, there are a number of pieces of legislation and policy which recognise the unique position of unpaid Carers.

Legislation

Carers Strategies (Wales) Measure 2010

The purpose of this Measure is to enable the National Assembly for Wales to legislate to introduce a new requirement on the NHS and Local Authorities in Wales ("the relevant authorities") to work in partnership to prepare, publish and implement a joint strategy in relation to carers.

http://www.assemblywales.org/bus-home/bus-legislation/bus-leg-measures/bus_legislation_meas-cs.htm

<http://www.assemblywales.org/bus-home/bus-business-fourth-assembly-laid-docs.htm>

<http://www.legislation.gov.uk/wsi>

Carers (Recognition and Services) Act 1995

This was the first piece of legislation that gave rights to Carers of all ages who provide regular and substantial care. This contains the core statutory responsibilities and requires local authorities to carry out an assessment of a carer's ability to provide and to continue to provide care, if the carer requests this, at the time of the assessment of the person they care for.

<http://www.legislation.gov.uk/ukpga/1995/12/contents>

Carers and Disabled Children's Act 2000

This Act gave Carers a right to ask for an assessment even when the person they were caring for refused an assessment. It also gave Local Authorities the power to provide services directly to Carers and to provide Direct Payments to Carers.

<http://www.legislation.gov.uk/ukpga/2000/16/contents>

Community Care (Delayed Discharges) Act 2000

It states that when a Carer asks for an assessment, Social Services in consultation with their partners in the NHS, must determine what service it will provide for the Carer when the cared for is ready for discharge.

<http://www.legislation.gov.uk/ukpga/2003/5/contents>

Carers (Equal Opportunities) Act 2004

This places a duty on Local Authorities to inform Carers of their right to a Carers assessment. It also ensures that Carers leisure, lifelong learning and employment opportunities must be taken into account when carrying out an assessment. It gives Local Authorities the power to enlist the help of Housing, Education and Health in

providing support to Carers.

<http://www.legislation.gov.uk/ukpga/2004/15/contents>

Children Act 1989

Young Carers can be identified as a 'child in need'.

<http://www.legislation.gov.uk/ukpga/1989/41/contents>

Children and Young Persons Act 2008

This requires local authorities to make adequate arrangements for short break provision for Disabled Children.

<http://www.legislation.gov.uk/ukpga/2008/23/contents>

Disabled Persons (Services, Consultation and Representation) Act 1986

This requires local authorities to have regard to the ability of the carer to provide or continue to provide care when deciding what services to provide to the disabled person.

<http://www.legislation.gov.uk/ukpga/1986/33>

Education Act 2002, Section 175

Section 175 concerns the duties of Local Education Authorities and governing bodies in relation to the welfare of children

<http://www.legislation.gov.uk/ukpga/2002/32/contents>

For each of the detaining Sections of the **Mental Health Act 1983** there are duties placed on Hospital Managers (and sometimes others) to provide written and oral information to patients (and in some cases their nearest relative, which may not be the same person as the carer incidentally). To support Hospital Managers to meet their duties, the Welsh Government have developed a series of leaflets.

All are available (in English and in Welsh) at:

<http://www.wales.nhs.uk/sites3/page.cfm?orgid=816&pid=33957>

Rights of Children and Young Persons (Wales) Measure 2011

The purpose of this Measure is to impose a duty upon the Welsh Ministers and the First Minister to have due regard to the rights and obligations in the United Nations Convention on the Rights of the Child (UNCRC) and its Optional Protocols, when making decisions of a strategic nature about how to exercise functions which are exercisable by them

<http://www.assemblywales.org/bus-home/bus-legislation/bus-leg-measures/business-legislation-measures-rightsofchildren.htm>

Mental Health (Wales) Measure 2010

- Part 2 of the Mental Health (Wales) Measure places statutory duties on mental health service providers in Wales (LHBs and local authorities) to ensure that all

patients in secondary mental health services have a care and treatment plan of a prescribed type, which is developed and reviewed, in partnership with the patient, by a care coordinator. Regulations made under this Part of the Measure require care coordinators to consult with certain other persons (including the patient's carer(s) in developing and reviewing care and treatment plans, and that certain persons (again, including the patient's carer(s)) should be provided with a copy of the plan, or relevant parts of the plan. The care coordinator has some discretion as to whether carers should be consulted and receive copies where the patient has not given their consent, against the patients wishes.

- In addition, this legislation enables carer(s) to request a review of the patient's care and treatment plan if they believe that this is necessary (although the care coordinator has some discretion as to whether a review is conducted following such a request).
- The Mental Health (Wales) Measure also places statutory duties on mental health service providers to make certain information available to patients in writing when they are discharged from secondary mental health services (including the reason for their discharge, and the actions to be taken in the event that the individual's mental health should deteriorate at some point in the future). Chapter 7 of the Draft Code of Practice which has been issued by the Welsh Government to support this Part of the mental Health (Wales) Measure states that service providers should consider providing this information to the individual's carer if it is believed that this would be appropriate and the individual is in agreement.

For further information on the requirements of this legislation, see the Welsh Government's Mental Health web pages:

<http://wales.gov.uk/topics/health/nhswales/healthservice/mentalhealthservices/?lang=en>

The United Nations Convention on the Rights of the Child (UNCRC)

The Articles of particular relevance to Children as Young Carers are:

Article 3 In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

Article 12 States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Article 13 The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.

Article 15 States Parties recognize the rights of the child to freedom of association and to freedom of peaceful assembly.

Article 19 States Parties shall take all appropriate legislative, administrative, social and

educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.

Article 28 States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity

Article 31 States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.

States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

Article 36 States Parties shall protect the child against all other forms of exploitation prejudicial to any aspects of the child's welfare.

<http://wales.gov.uk/topics/childrenyoungpeople/publications/uncrcarticles/?lang=en>

Work and Families Act 2006

This came into force in Wales in April 2007. It requires employers to consider requests from people with caring responsibilities to work flexibly.

<http://www.legislation.gov.uk/ukpga/2006/18/contents>

Government – Carers Policy Documents

Caring about Carers: A Strategy for Carers in Wales and associated Implementation Plan (WG, 2000)

The Carers Strategy in Wales seeks to meet the legitimate needs of carers for real practical support and assistance across the five priority areas of Information; Health and Social Care; Support; Young Carers and Carers and Employment

<http://wales.gov.uk/topics/health/publications/socialcare/carers/carersreport3?lang=en>

http://wales.gov.uk/topics/health/publications/socialcare/carers/strategy_carers_wales?lang=en

Carers Strategy in Wales – the Action Plan (WG 2007)

Reinforces the Welsh Government's commitment to improve information for Carers

<http://wales.gov.uk/topics/health/publications/socialcare/carers/carersactionplan?lang=en>

The Programme for Government commits the Welsh Government to refreshing the Carers Strategy for Wales. Work will get underway on this in the Spring of 2012.

Challenging the Myth 'They Look After Their Own' (WG 2003)

This is the Welsh Government's good practice Guidance for working with BME Carers. The Guidance challenges the view held by many health and social care professionals that BME people 'look after their own' thus adversely affecting the quality of care given to particular communities. The Guidance provides information to care managers for assessing and planning support packages for BME Carers.

<http://wales.gov.uk/topics/health/publications/socialcare/carers/challengingthemyth?lang=en>

Government - General Policy Documents

Building Strong Bridges (WG 2002) and Designed to Add Value (WG 2008)

The Guidance is about strengthening partnership working between the Third sector and the NHS in Wales. It sets the strategic direction for the Third sector in supporting health and social care through the following themes:

- Stronger partnership working within the Third sector and between the sectors
- Improved service planning, delivery and resourcing
- Supporting self care and independence
- Improving access to services for specific communities
- Promoting and improving health and well being
- Reducing hospital admissions and improved discharge

<http://wales.gov.uk/topics/health/publications/health/strategies/3361338/?jsessionid=jw3BMYwGZNPQFVC5HplZn1rQTTDDpbQ9b1JRjvmZ7hL1LhvJCvfx!-42672990?lang=en>

<http://wales.gov.uk/topics/health/publications/health/strategies/designedaddvalue/?jsessionid=jw3BMYwGZNPQFVC5HplZn1rQTTDDpbQ9b1JRjvmZ7hL1LhvJCvfx!-42672990?lang=en>

Children and Young People: Rights to Action (WG)

This paper addresses policy and provision of services for children and young people in Wales

<http://wales.gov.uk/topics/childrenyoungpeople/publications/rightstoaction/?lang=en>

Children and Young People's Wellbeing Monitor for Wales (WG, 2011)

defines young carers as 'children and young people who help look after a member of the family, who is sick, disabled, has mental health problems or is affected by substance misuse.'

<http://wales.gov.uk/about/aboutresearch/social/latestresearch/cypwellbeingmonitor/?lang=en>

Creating a Unified and Fair System for Assessing and Managing Care (WG 2002)

This Guidance includes the Unified Assessment Process. The Guidance says that there should be a Carer domain where there is a Carer the practitioner should 'ascertain the nature of that support, the strength of the caring relationship, and whether the Carer requires support and services, either to help them to continue to

care for the older person or in their own right.' A separate Carers assessment should also be offered.

<http://new.wales.gov.uk/publications/circular/circulars2002/NAFWC09a2002?lang=en>

Framework for the Assessment of Children in Need and their Families (WG 2001)

This Framework assesses whether a child is in need and how that child and family might best be helped. The effectiveness with which a child's needs are assessed will be key to the effectiveness of subsequent actions and services and, ultimately, to the outcomes for the child.

<http://wales.gov.uk/topics/childrenyoungpeople/publications/childreninneed/?lang=en>

Fulfilled Lives, Supportive Communities – A Strategy for Social Services in Wales over the next Decade (WG 2007)

This document sets a vision for the future of Social Services and Social Care services in Wales and a 10 year Strategy for achieving it. It stresses the importance of recognising the contribution of Carers and supporting them in their caring role.

<http://wales.gov.uk/topics/health/publications/socialcare/strategies/lives/?lang=en>

Healthcare Standards for Wales (WG 2010) set out the Welsh Government's common framework of standards to support the NHS and partner organisations in providing effective, timely and quality services across all healthcare settings.

<http://www.nhswalesgovernance.com/display/Home.aspx?a=130&s=2&m=0&d=0&p=0>

Hospital Discharge Planning Guidance (WG 2005)

The Guidance states that patients and their Carers/families are fully engaged at all stages in the hospital discharge process. Patients and their families and/or Carers are provided with written and verbal information in a range of formats appropriate to them, taking into account any sensory or spoken language needs. The information should include details of arrangements and any relevant information regarding their future treatment and care.

<http://wales.gov.uk/publications/circular/circulars05/1560146/?lang=en>

National Dementia Vision for Wales and associated Dementia Action Plans (WG 2010)

The Vision is for services to develop more closely integrated services, more comprehensive programmes of care and a greater awareness and understanding of the needs of people with dementia and those close to them, such as their families, friends and carers. The associated action plans focus on:

1. Improved service provision through better joint working across health, social care, the Third sector and other agencies;
2. Improved early diagnosis and timely interventions;

3. Improved access to better information and support for people with the illness and their carers, including a greater awareness of the need for advocacy;

4. Improved training for those delivering care including research

<http://wales.gov.uk/topics/health/publications/health/guidance/dementia/?lang=en>

NHS Annual Quality Framework

The Framework is a step change towards measuring an outcome focussed, quality driven service. It moves the focus away from targets and allows greater flexibility for the NHS to innovate and improve services.

<http://howis.wales.nhs.uk/sites3/page.cfm?orgid=407&pid=43132>

National Service Framework for Adult Mental Health – Raising the Standard (WG 2005)

The NSF makes a number of references to Carers:

Standard 2 Service user and Carer empowerment. Its aim is to encourage the full and genuine participation of persons cared for and Carers in all aspects of mental health services, including planning and commissioning.

Key Action 8 Carers have a statutory right to their own assessment and if assessed as eligible for support, a written care plan. The special needs of young Carers are to be taken into account.

Key Action 10 People with mental health problems and their Carers have the same needs for friendship and social, leisure/recreational and educational/training/lifelong learning activities as any other person in the community.

Standard 7 Effective client assessment and care pathways. The aim is to have effective high quality care based on the best evidence and including provision for the medical, physical, psychological and social needs of persons cared for and Carers.

Key Action 39 The needs of vulnerable children and young people whose parents or guardians have mental health problems are to be considered very carefully. There is to be careful planning to ensure their needs are fully taken into account especially in situations where they are acting as Carers.

<http://wales.gov.uk/topics/health/publications/health/reports/raisingthestandard?lang=en>

National Service Framework for Children, Young People and Maternity Services (WG 2005)

It identifies Young Carers as Children in special circumstances. It says that, 'Children who fall within the remit of children in special circumstances should be identified local through the Health Needs Assessments carried out to inform the local HSCWB strategies.'

<http://wales.gov.uk/topics/childrenyoungpeople/publications/nsfchildrenyoungpeoplematernity/?lang=en>

National Service Framework for Older People in Wales (WG 2006)

This highlights supporting Carers to enable older people to remain in the community. It says that, 'Carers play a crucial role in helping people to remain living in their own

homes, and avoiding dependency on formal care services. The needs of Carers should therefore be assessed and support provided to enable them to continue with their caring role, to maximise outcomes for the Carer and the person cared for.

<http://wales.gov.uk/topics/olderpeople/publications/nationalserviceframeworkolderppl/?lang=en>

Paper on Sustainable Social Services in Wales: A Framework for Action (WG 2011)

The paper puts in place a framework for meeting the challenges facing social services in the next decade and beyond, and sets out priorities for action. It aims to reshape and refocus social services in order to ensure that they remain strong, and can continue to meet citizens' needs and aspirations.

<http://wales.gov.uk/topics/health/publications/socialcare/guidance1/services/?lang=en>

Pooled Budgets advice notes (WG)

<http://wales.gov.uk/topics/improvingservices/poolbudgets/?lang=en>

Setting the Direction (WG 2010)

This document recognises the need to change the approach to developing both policy and service delivery models for primary and community care

<http://wales.gov.uk/topics/health/publications/health/strategies/settingthedirection/>

Schools Counselling Service Strategy (WG)

This document sets out the Welsh Government's strategy for developing school-based counselling services for children and young people that are of a high standard.

<http://wales.gov.uk/topics/educationandskills/publications/guidance/counsellingservicestrategy/?lang=en>

Signposts Two – Putting Public and Patient Involvement into Practice (WG 2003)

This builds on the original Signpost 1 guidelines in order to achieve better practice and performance. It is designed to be used primarily by NHS organisations in Wales, but it is hoped that others with an interest in public and patient involvement, such as Community Health Councils and Third sector organisations, will also find this guide to be a valuable resource.

<http://www.wales.nhs.uk/sites3/page.cfm?orgid=420&pid=2470>

Together for Health (WG, 2011)

This is the Welsh Government's five year vision for the NHS in Wales. This document recognises the important contribution that carers make to many lives.

<http://wales.gov.uk/topics/health/publications/health/reports/together/?lang=en>

Other Resources

Care Council for Wales: Care at Home

<http://www.ccwales.org.uk/development-and-innovation/adult-workforce/care-at-home>

Care Council for Wales: Codes of Practice for Social Care Workers

These contain standards that carers can expect from the social care workforce

<http://www.ccwales.org.uk/registration-and-conduct/confidence-in-care/the-codes-of-practice>

The Care Council for Wales provide a range of staff training and development products that can be used by social care staff involved in training carers

A Carer Proofing Toolkit is under development by the WLGA-sponsored Carers Officers Learning and Improvement Network

Carers Officers Learning and Improvement Network

<http://www.ssiacymru.org.uk/index.cfm?articleid=4060>

Carers UK: Valuing Carers 2011

<http://www.carersuk.org/professionals/resources/research-library/item/2123-valuing-carers-2011>

Department of Health: Nothing About Us Without Us

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006200

Expert Patients Programme: Looking After Me

<http://www.expertpatients.co.uk/course-participants/courses/looking-after-me-1>

General Medical Council: Guidance for Doctors – Confidentiality

http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp

General Medical Council: Guidance for Doctors – Consent: patients and doctors making decisions together

http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_index.asp

NLIAH: National Principles for Public Engagement

These Principles aim to offer a consistent approach and good standard for public engagement across Wales

<http://www.wales.nhs.uk/sitesplus/829/page/53159>

NLIAH/WG/ British Heart Foundation/Diabetes UK Cymru/Welsh Kidney Patients Association/The Stroke Association: Guidance on Involving Adult NHS Service Users

and Carers

<http://www.wales.nhs.uk/sitesplus/829/page/51396>

NLIAH: Passing the Baton provides guidance on a broad range of subjects from the basic processes of discharge through to the complexities of current legal obligations. The Guide touches on the information and knowledge necessary to ensure that individuals experience a safe and timely transfer of care or discharge from hospital.

<http://www.wales.nhs.uk/sitesplus/829/page/36467>

SSIA: Getting Engaged Programme

Developing strategies to maximise user and carer engagement with the planning and delivery of social services

<http://www.ssiacymru.org.uk/index.cfm?articleid=4516>

For Good Practice in supporting Carers and the benefits of that to patients, Carers and NHS resources, see BMJ 2004;328:1099 and 1102 (8 May 2004)

<http://bmj.bmjournals.com/cgi/content/full/328/7448/1085>

WLGA: Service Improvement Datasets (for Adults and Children)

<http://www.dataunitwales.gov.uk/NPI.asp?cat=490>

Childrens Society and the Princess Royal Trust for Carers: Include Project - Young Carer definition

Annex 2 - Interpretation of Regular and Substantial Care

Introduction

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 impact of the whole caring situation.

The term 'substantial and regular' is not defined in the 2000 Act or in this Guidance. In any given situation, the test that a practitioner should apply will relate to the impact of the caring role on the individual carer. In particular the practitioner will need to address the following questions:

- Is the caring role sustainable?
- How great is the risk of the caring role becoming unsustainable?

Example

All substantial and regular carers have a right to an assessment. There should be no assumption that a 'main' or 'primary' carer is the only substantial and regular Carer. Where there are children in the family, there are important additional issues that may need to be addressed in the initial assessment.

Mr Griffiths is 86. He has severe arthritis. He needs help to get up in the morning, to wash, to get into his wheelchair, to use the toilet, to undress and to go to bed. Mrs Griffiths is 84. She is helped by her daughter Tessa who is 44 and lives near by.

Mr Griffiths is eligible for community care services. There are potentially two substantial and regular carers here. Tessa is willing, with appropriate instruction, availability of equipment and so on, to help Mr Griffiths into his wheelchair etc without undue risk to her health. Mrs Griffiths is not able to carry out this task, but, if Tessa carries out the physically demanding tasks, Mrs Griffiths is quite happy to carry out all the other associated intimate care tasks. Mrs Griffiths sees herself primarily as a wife and is quite content with her caring role since her husband would have done the same for her if the situation were reversed. Tessa, on the other hand, is also trying to hold down a job, making it impossible for her to contribute at key times when Mrs Griffiths needs her help. She is also bringing up children and without help in her caring role she will not be able to give them the support they need from her as a mother.

Children and young people affected by caring situations

An initial assessment of Adult Carers and service-users must always clarify whether they have a parenting role. Sometimes children of the family may be in need as a result of the impact of disability or illness on a family member. If so Children's Services staff should be involved and an assessment undertaken following the guidance set out in *Framework for Assessing Children in Need and their Families* (see Annex 1). Young carers should not be expected to carry inappropriate levels of caring which have an adverse impact on their development and

life chances. It should not be assumed that children should take on similar levels of caring responsibilities to adults. Services should be provided to parents to enhance their ability to fulfil their parenting responsibilities under the Children Act 1989. An assessment of family circumstances is essential. This may well call for good quality joint work between Adult and Children's Social Services as well as co-operation from schools and health care workers.

The person cared for should be receiving sufficient services so that the young person is not undertaking an inappropriate caring role. In particular, assessment under the *Framework for the Assessment of Children in Need and their Families* (see Annex 1) and the 1995 Act will be aimed at ensuring that the child is not undertaking a level of responsibility that may undermine their ability to participate in education, including further and higher education, normal leisure activities and social interaction with their peer group. Any such services provided will be designed not to support them in their caring role but rather to ensure that they do not undertake a caring role that is inappropriate.

Support should be aimed primarily at helping any disabled or other adults with parental responsibility to carry out their parental role and to remove inappropriate responsibilities from children. Care should be taken that children do not become 'institutionalised' as carers. They should be allowed to be children, first and foremost.

It should be noted that the caring role is not necessarily one focused simply on caring tasks, such as personal care, moving and handling. Sometimes, as in mental health situations, the role may be to provide emotional support or intensive supervision rather than physical or personal care. Here too the impact of caring situations will differ with the age of the Carer.

Under Section 17A of the Children Act 1989, Direct Payments can only be provided to those families and young people who would otherwise be receiving services under Section 17 of the 1989 Act. Assessment of need, for either those services or a direct payment in lieu, should be based on the *Framework for the Assessment of Children in Need and their Families*, which provides a systematic approach to assessing the child's developmental needs, the capacities of their parents to respond to these needs appropriately, within their wider family and environmental context. The format of the assessment should be the same whether it is thought likely that the outcome will be the provision of a service or a Direct Payment. Assessments should be seen as positive opportunities to identify and respond to the range of needs of children and families. Assessments should not focus on a single need or whether a particular service is available.

In many cases, disabled children will already have been assessed by other services (for example, Education and Child Health services). Families with disabled children often report being over-burdened by uncoordinated assessments. The outcomes of the various assessments should be co-ordinated and integrated in order to give a comprehensive picture of the needs of the child and any relevant provision.

Assessments should clarify the additional support and advice which may be necessary to ensure that the Direct Payments are effective. Organisations may wish to consider developing a key worker system as a way of supporting young people who have opted for Direct Payments. Such a key worker could be a personal adviser, a social worker or a member of staff from a voluntary organisation or a Centre for Independent Living.

Caring at a distance and caring across boundaries

Particular difficulties may be faced by Carers who care for people who live a long way away from them. This will be especially true where they care for more than one person, and/or where they are caring for someone who uses or could use services in a different Organisation area.

The Carer's Assessment will be particularly crucial in these situations, since a Carer's role may not appear substantial and regular if the assessment does not take into account the inconvenience of caring at a distance, or if one Carer's Assessment relating to one cared for person in one Organisation area is carried out without regard for the Carer's other responsibilities.

Organisations will need to work in partnership with neighbouring and other Organisations – many carers commute long distances to provide care at weekends. The basic principles behind such joint work should be as follows:

- Where the Carer cares long distance for only one cared for person and that person is eligible for support, the community care service-user's home Organisation area has responsibility for the Carer's Assessment and provision of services even if Carers' services need to be provided in a different Organisation area.
- Where the Carer cares for more than one person in more than one Organisation area, but only one cared for person is eligible for community care services, the home Organisation area of the eligible cared for person has responsibility for the Carer's Assessment and for leading on any co-ordination that may be required between Organisations.
- Where two cared for people in two different Organisation areas are eligible for community care services, those Organisations should agree how a Carer's Assessment may best be conducted ensuring between them that all relevant information is available and negotiating how Carers services may need to be provided to ensure the sustainability of the joint caring roles if this outcome is in the best interests of the Carer.

Neighbouring Organisations should agree and publish protocols covering carers' assessments in such situations.

In relation to carers who live in Wales but the person they care for lives in England, this Guidance expects the default position to be that carers should still be provided with as much information as possible to enable them to carry out their caring role effectively. It is likely that border LHBs and local authorities already have in place a variety of arrangements with their neighbour English authorities in which case the content of the Measure and associated Regulations and Guidance can be shared with them.

Annex 3 - Examples of Notable Practice in the Provision of Services to Carers

Each of the following services was put forward through the consultation exercise and cited as being of benefit to Carers.

Please also see the Good Practice Wales website: <http://www.goodpracticewales.com/>

Alzheimers Society Cardiff Carers Bus

http://alzheimers.org.uk/site/scripts/news_article.php?newsID=79

Alzheimers Society Carers Information Programme

<http://alzheimers.org.uk/site/scripts/documents.php?categoryID=200343>

Carmarthenshire Stroke Association Stroke Health Improvement Project

<http://www.cavs.org.uk/stroke-healthcare-project-carmarthenshire/>

Ceredigion Investors in Carers GP Practice Scheme

<http://www.ssiacymru.org.uk/index.cfm?Articleid=2796>

Ceredigion Carers Charter

<http://www.ssiacymru.org.uk/index.cfm?articleid=4347>

Disability Advice Project

<http://www.dap-wales.org.uk/>

MIND Cymru

Here is a link that will take you to a directory of local services

http://www.mind.org.uk/mind_cymru/landing

Hafal

Here is a link that will take you to a directory of local services

<http://www.hafal.org/>

Macmillan Cancer Support services for carers of people affected by cancer, with the Princess Royal Trust for Carers

<http://www.carers.org/local-centre/bridgend/services/macmillan-family-information-and-support-service-0>

Parkinson's UK Cymru Information and Support Service

http://www.parkinsons.org.uk/local_to_you/regional_teams/wales/wales_contacts.aspx

Newlife Nurse Service and Equipment Grant Service

<http://www.newlifecharity.co.uk/docs/news/EkEZVApppECZimEpnv.shtml>

Powys Wellbeing Training Brochure

<http://www.pavo.org.uk/support/training-from-other-providers.html#c3890>

Swansea Young Carers Education Development Worker

<http://www.swanseayoungcarers.co.uk/2009/11/snpt-young-carers-project.html>

Swansea Carers Development Worker for the Bangladeshi Community

<http://www.ssiacymru.org.uk/index.cfm?articleid=1283>

Welsh Ambulance Services NHS Trust Partners in Healthcare

<http://www.ambulance.wales.nhs.uk/TheRoom/Default.aspx?pageId=206&lan=en>