

# North Wales Carers Information and Consultation Strategy

2012 - 2015

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## 1. Introduction

Carers\*<sup>1</sup> are a vital and central part of the whole health and community care system; they make an enormous contribution to society. It is important that statutory organisations acknowledge this, listen to their point of view, acknowledge their expertise and work in partnership with them to respond practically to their needs.

Local Authorities (usually through their Social Services Departments) have long had responsibility for meeting carer's needs. However, evidence indicates that 4 out of 5 carers state that their first point of contact with any statutory agency is via the community based health services. To ensure earlier identification and support for carers, and enhance the existing service provision the Carers Strategies (Wales) Regulations 2011 were passed and on 1<sup>st</sup> January 2012, the Carers Strategies (Wales) Measure (2010) came into force.

The Carers Strategies (Wales) Measure (2010) requires Betsi Cadwaladr University Local Health Board (BCUHB) and the 6 Local Authorities in North Wales to work in partnership with carers, statutory and non-statutory organisations to prepare and publish a Carers Information and Consultation Strategy setting out how they will work together to assist and include carers in the arrangement made for those they care for.

As a result of this, In January 2011 partnership organisations in North Wales formed the North Wales Carers Leads Strategic Group (NWCLSG). The aim of this group is to utilise an integrated approach for the development of the North Wales Carers Information Strategy. This partnership consists of representatives of BCUHB, Local Authority Carers Leads and various Third Sector Carers Organisations.

This 3 year strategy places an emphasis on the statutory duties that BCUHB will fulfil in order to comply with the Carers Strategies (Wales) Measure 2010; each local authority in North Wales also has their own Carers Strategy and the intention is that this strategy will complement the existing Local Authority strategies rather than supersede them.

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<sup>1</sup> When referring to carers in this document, it means unpaid carers of all ages and background unless specified otherwise

## **2. Definition of a Carer**

A carer is a person 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

The above definition does not include an individual who provides or intends to provide that care:

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

(Welsh Government 2012)

It is acknowledged that although this definition is useful for clarification to assist professionals to identify carers; A significant number of people with caring responsibilities do not readily identify themselves as carers and understandably see themselves primarily as a parent, spouse, son, daughter, neighbour or friend. (HM Government 2010)

There are additional challenges in the identification of young carers as these children often remain “hidden” from the statutory services due to concern about the reaction of others and have the added fear of “being taken into care” and bullying by their peers, this is particularly the case for children whose parents have drug and alcohol problems.

## **3. Vision**

To develop a culture that understands and respects the experience and knowledge of carers. The needs of carers will be mainstreamed into everyday practice to ensure that carers are supported in their caring role, and are able to maintain their own independence whilst protecting their health and wellbeing.

## **4. Scope**

This strategy sets out the direction for the next 3 years and provides an overarching framework to support collaborative working with service users and carers.

The strategy is relevant to:-

- Carers and service users
- Staff employed by BCUHB
- Staff employed by the 6 local authorities in North Wales
- GP's and practice staff
- Independent contractors
- Staff in residential homes, commissioned to support carers that are statutorily funded
- Stakeholders and partnership agencies, including the Community Health Council, Third Sector Voluntary Organisations and community groups

## **5. Carers Profile**

### **5.1 National Profile**

In a study carried out by the Care Council for Wales (2010) it was estimated a staggering 96% of the annual care hours in Wales are provided by unpaid carers with the remaining 4% provided by local authorities and independent providers.

The 2001 Census identified that there are 340,000 carers in Wales (equivalent to 11% of the population), and this number was projected to rise to 369,628 by 2011, of these:-

- 61.1% provide care for between 1-19 hours per week
- 12.6% provide care for between 20-49 hours per week
- 23.7% provide care of 50 hours or more per week.

The 2001 Census identified that there were over 4,600 young carers (age <18) in Wales. . However given the census makes no mention of alcohol or drug problems, carers' organisations believe the figures are much higher with many young carers remaining 'hidden' due to the stigma attached to these conditions. More recently in a report commissioned on behalf of the Children Commissioner for Wales, colleagues in Welsh Government have quoted the number of young carers in Wales at 11,000 (Powys Carers Service 2009).

### **5.2 North Wales Profile**

More recent data provided from the Welsh Health Survey 2008 (source [www.daffodilcymru.org.uk](http://www.daffodilcymru.org.uk) ) would indicate that the number of carers in North Wales has increased and this increase is predicted to rise year on year due to the ageing population.

**Table 1: Predicted number of carers in North Wales by 2015(Welsh Health Survey 2008)**

Age of carer	No. of hours of unpaid care provided per week			Total
	<19 hrs	20-49 hrs	>50 hrs	
<b>16-24</b>	7,896	2,254	2,871	<b>13,021</b>
<b>25-64</b>	37,864	10,327	13,769	<b>61,960</b>
<b>65 &gt;</b>	17,334	4,727	6,303	<b>28,364</b>
<b>Total carer population for BCUHB</b>				<b>103,345</b>

It is acknowledged that the current available data is an underestimate of the total carer population as this data only includes young carers from the age of 16; whereas anecdotal evidence from carer support organisations, children’s charities and local authority carers leads would indicate that there is a significant number of young carers below the age of 16.

## **6. Legislation**

There is a range of legislation that places a duty on local authorities and the health service to provide good quality support to carers (see appendix 1). This strategy has been produced in response to the most recent legislation; the Carers Strategies (Wales) Regulations were passed in December 2011. On 1<sup>st</sup> January 2012, the Carers Strategies (Wales) Measure came into force and the guidance for implementation of the Measure was issued to Local Health Boards and Local Authorities.

For the first time, this Measure places a legislative duty on the NHS in relation to services for carers in Wales.

## **7. Impact of Caring**

Whilst there are many rewards from providing care to a loved one, there is a growing body of evidence indicating 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.

*"I get tired at times and lonely.... We used to do everything together but this is not possible now"*

*"Sometimes I am very stressed.... Need time for me"*

*"My Mum has Alzheimer's and both my sister and I work full time.. we find it difficult to juggle jobs and care for our mum"*

*"I feel isolated...."*

(quotes from North Wales Carers Leads Strategy Group Survey 2012)

## 7.1 Adult Carers

In the 2001 Census it was identified that carers in Wales were a third more likely to suffer ill health.

Carers who provide high levels of care for sick or disabled relatives and friends are more than twice as likely to suffer poor health compared to people without caring responsibilities. An analysis of the census demonstrates that nearly 21% of carers providing over 50 hours per week of care say they are in poor health compared to nearly 11% of the non-carer population. In a more recent study 70% of older carers reported caring to be having a devastating impact on their mental and physical health. (The princess Royal Trust for Carers 2011)

The recent Carers Week survey 'In Sickness and in Health' polling some 3,400 carers across the UK cited the main issues affecting their health as:

- anxiety or stress (91 per cent),
- depression (53 per cent),
- injury such as back pain (36 per cent),
- high blood pressure (22 per cent)
- the deterioration of an existing condition (26 per cent).

**Older carers, those 60+, are the fastest growing demographic of carers and also those most likely to have multiple caring responsibilities.**

Although on average, 12% of the population provide unpaid care for a friend or family member, this increases to 18% for those aged 55–64, 16% for those aged 65–74 and 13% for those aged 75 and above

## 7.2 Young Carers




Young carers report positive and negative elements to providing care; the positive aspects are that they have sense of closeness to the person(s) they are caring for, they feel mature and value the skills they gain from caring. (Social Care Institute for Excellence 2005)

The research evidence indicates that the impact of the caring role on young carers is far reaching and includes the following risks:

- Difficulties in attending school
- Truancy
- Under achievement
- Isolation
- Subject to bullying from peers
- Mental and Physical ill health
- Poverty
- Stress

(Social Care Institute for Excellence 2005;  
Crossroads Caring for Carers & The Princess Royal Trust for Carers,  
November 2008)

It is also acknowledged that these risks are particularly acute for young people who are caring for parents who misuse alcohol or drugs and parents with mental health problems. (Crossroads Caring for Carers & The Princess Royal Trust for Carers, November 2008)



*“None of her school friends know what her life is like at home.”.. “I don’t tell them because they make fun of people who have things like my mum and my brother do”*

*“Sometimes I wish I could go out with my friends or have them to stay but I don’t feel jealous of them. I think I am a bit more grown up than them.*

*“I always worry about him but I know he is being looked after. I can’t really talk about it with my friends because they don’t really understand what it is like*

*“When I try to talk to people like doctors or social workers some of them don’t really listen to me because they think I am too young”*

The Powys Carers Service (2009) report is the first comprehensive piece of research examining first hand experiences of young carers here in Wales.

*“Young carers are expected to take on many responsibilities which are inappropriate for their age and often with little support. Paid carers receive training and support that most young carers as well as adult carers do not receive.”* Many young carers for example (50% of those surveyed) administer medicines to those they care for and yet 73% said they received no training on how to do it. Manual handling is another similar story.

## **8. Core Principles for Working with Carers**

This strategy and accompanying action plan will be underpinned by the following core principles:-

- Carers are equal partners in care

- No assumptions are made regarding a carer's capacity or carers' capacities and willingness to take responsibility for, or continue to care
- Support carers to be as physically and mentally well as possible and prevent ill health
- Carers will be involved in decision making and choices at all levels and at all stages in the caring role, in a positive, timely and proactive way
- Provide care and support with flexibility and understanding in a personalised way that reflects the circumstances, cultural background and lifestyle of the carer.
- Respect and recognise that carers will have their own support needs, rights and aspirations, which may be different from those of the cared for person.
- Identify, support and enable both children and young people who are carers to be young as well as carers. Provide support and a safe environment to help them learn, develop and enjoy positive childhoods
- Recognise the experience of carers as the caring role ends and after it has ended and offer support to carers accordingly

(Skills for Care 2011)

## **9. Aims of the Information and Consultation Strategy**

The five key aims of this strategy are to ensure:

- Carers' issues are mainstreamed into the everyday working practices of NHS and other staff.
- Carers are allowed to make a choice about the level of care they wish to provide
- Core information for carers is available and accessible regardless of where the carer lives
- Carers are recognised and listened to; ensuring they are true partners in care
- Staff training and development will enable staff at all levels to support carers appropriately

## **10. Objectives**

**10.1** All professionals within the NHS and Local Authorities will be made aware of their responsibilities in relation to the Carers Strategies (Wales) Measure through opportunistic awareness raising and staff training.

**10.2** Carers will 'be identified at the earliest opportunity.

**10.3** Carers will be given sufficient timely information<sup>2</sup> according to their individual needs.

**10.4** Where patient consent is withheld, carers will be provided with as much information that can be shared without breaching patient confidentiality to enable them to carry out their caring role safely

**10.5** Every carer will be informed of their legislative right to an independent assessment of their support needs as a carer

**10.6** Carers will be involved as a matter of course in all decision making processes around care management

**10.7** NHS staff are able to signpost identified carers to carer support organisations

## **11. What are the Current Organisational Arrangements for the Benefit of Carers in North Wales?**

BCUHB and the 6 local authorities' commission the services of Third Sector Carers Organisations and provide core funding for these services. These organisations act as the main resource for carers, providing information, training and support. The local authorities and health board also provide funding for respite care and short breaks for carers.

BCUHB will continue working with statutory partners, independent providers and the Third Sector Organisations to develop and align current services to meet the needs of Carers and the requirements of the Carers Measure and to ensure sustainability of services for the benefit of Carers.

## **12. How does this Strategy link with other National and Local Policies/Strategies?**

In recognition of the importance of the role carer's play and the need to provide support to them in their work the *Carers (recognition and Services) Act 1995* was passed (see Appendix 1, A1.2). Since then a number of key pieces of legislation and national strategies have been produced to ensure that carers are supported in their role. The NWCLSG has referred to the legislation outlined in Appendix 1 and the following key national and local strategy documents to inform their work:

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<sup>2</sup> All written information will be available in a bilingual format (Welsh and English)

## 12.1 National Strategies

- **Carers Strategy for Wales Action Plan (Welsh Assembly Government 2007)**; this strategy recognised that carers have need of their own and set out the strategic direction to ensure better assessment and care management arrangements were in place and there was more constructive engagement with carers as key partners in care,
- **Older Peoples National Service Framework (Welsh Assembly Government, 2006)**; this framework advocated involving carers in the Unified Assessment process and providing them with up to date information.
- **Together for Health (Welsh Government 2011)**; this five year vision for the NHS in Wales emphasises the importance of utilising the 3<sup>rd</sup> Sector to support carers.
- **Wales Accord for Sharing Personal Information (Welsh Assembly Government 2010)**; this is a framework outlining a common set of principles and standards which govern the activity of information sharing. This Accord will be used to develop an Information Sharing Pathway for Carers.
- **Sustainable Social Services for Wales: Framework for Action (Welsh Government 2011)**; this framework sets out the priorities for reshaping social services and emphasises that service users and carers will be given a stronger voice and greater control over the services they use.

## 12.2 Local Strategies/Policies

- **Local Authority Carers Strategies.** Each of the six local authorities has a Carers Strategy in place which outlines the plans, procedures and services available for carers in their local community.
- **The Mental Health (Wales) Measure 2010: Part 1 Scheme: Local Primary Mental Health Support Services;** this is a joint regional scheme for North Wales which determines how the statutory partners are to formally meet the requirements of Section 2, Part 1 of the Measure. This scheme, where appropriate includes reference to carers as partners in care.
- **Health Social Care and Wellbeing Strategies.** All six local authorities have a Health Social Care and Wellbeing Strategy in place and each refers to the importance of supporting carers and outlines the plans and objectives in relation to carers.
- **Children and Young Peoples Partnerships.** All six local authorities have a Children and Young People Partnership group and plans and refer to identification and support of young carers
- **BCUHB Equalities and Diversity policy**
- **BCUHB Discharge Protocol (2012).** This protocol outlines the discharge processes for patients within BCUHB and its six local partner authorities. The protocol refers to carers throughout the various

processes and emphasises the importance of involving carers in the discharge process as an equal partner in care.

### 13. Where do we need to be?

There are a number of “pockets of good practice” in North Wales in relation to service provision for carers, however, in some areas carers feel isolated, excluded from care planning and unsupported (North Wales Carers Survey 2012).

In order to achieve our vision of mainstreaming carers’ issues into everyday practice within BCUHB, there are a number of challenges ahead and this strategy outlines the key actions that will need to take place.

As this is a 3 year strategy the work programme for the partnership (NWCSLG) will be arranged as follows:

<b>Year 1</b>	<b>Year 2</b>	<b>Year 3</b>
Engage and consult with carers and relevant stakeholders	Pilot service developments in relation to information provision and consultation (using improvement methodology)	Evaluate Service developments
Review current information provision and consultation with carers	Develop systems for evaluation (to include outcome measures)	Engagement and consultation events with carers for formal evaluation of the strategy
Explore options for service development	Spread service development initiatives	Make recommendations
Develop systems and processes to support service development	Monitor service provision (by continuous feedback systems)	Agree Changes

(NB: this is an outline of how the work programme will be progressed; a detailed action plan will be developed outlining how these broad actions will be undertaken)

#### 13.1 Identification and Signposting of Carers

Carers have told us that they often have had to wait until a crisis happens before they have any support. Systems and processes will be put in place at BCUHB to ensure carers are identified at the earliest opportunity and they will be signposted to the relevant agencies for support. This requires carer awareness to be integrated into everyday working practices; this will be achieved by:

### **Key Actions: Identification and Signposting of Carers**

#### **Year 1**

- Provision of Carer Awareness training for all frontline staff at BCUHB and General Practitioner Practices, which emphasises the need for early identification of carers.
- Develop BCUHB Carer Information leaflet(s) (which includes a section on young carers –see Appendix 2). These leaflets will be available in all clinical areas within the Health Board (to include GP surgeries/community clinics etc). The information leaflets have been developed following consultation with carers via the North Wales Carers Survey (2012) and focus groups at the various carers support groups. The aim of these leaflets is to provide an initial introduction to the carers support agencies and inform carers of their rights to a Carers Needs Assessment.

#### **Year 2**

- Adapt recording systems to ensure questions in relation to carers will be included as part of the routine history taking process when health service users come in to contact with a service.

## **13.2 Referral for Carer Support**

There are a number of carer support organisations in North Wales (see appendix 3). Carers have told us that the carer support organisations have been an *“invaluable source of information”* and find them very helpful for *“befriending”* and *“just knowing there is someone at the end of the phone”*. (North Wales Carers Survey, 2012)

Referrals to these organisations are low from health organisations and tend to be self referrals or via social workers, often the referrals are when the carer has reached the end of their “tether” or when a crisis occurs. The early identification of carers and referral by the health professionals to the support organisations should improve this situation (see 12.2.1 below).

### **13.2.1 Carers Needs Assessments**

These are currently undertaken by the Local Authority or in some areas of North Wales the Carer Support Organisations are commissioned to carry out assessments on behalf of the Local Authorities. The assessment process is designed to assess what help and support the carer requires to undertake the caring role as well as maintaining their life outside of this role. Early identification of carers by Health Board staff will enable carers to be referred for this assessment in a timelier manner this will be facilitated by:

### **Key Actions: Carers Needs Assessments**

#### **Year 1**

- Develop a formal referral system for NHS staff to refer adult carers for support or/and a Carers Needs Assessment
- NHS staff training will educate all staff about the specific issues for young carers and the need for referral for support using the “Child in Need” process
- Develop systems to monitor referrals to Carer Support organisations
- Develop systems to monitor referrals for Carers Needs Assessments

#### **Year 2/3**

- The impact of earlier identification of carers is unknown; therefore the potential for an increase in the number of referrals for a Carers Needs Assessment will be monitored to consider capacity issues and implications for future services
- The partnership will explore solutions in anticipation of rise in demand for Carers Needs Assessment and services

### **13.2.2 Sharing of Carers Needs Assessments**

The Carers Strategies (Wales) Measure 2010: guidance document (Welsh Government 2012) outlines a best practice recommendation that (with carers consent) organisations, including GP’s, should request to see a copy of the Carers Needs Assessments. This will help staff to better meet the information, communication and consultation needs of carers; this will be facilitated by:

### **Key Actions: Sharing of Carers Needs Assessments**



## **Year 2**

- Develop an Information Sharing Protocol in partnership with Third sector, Local Authorities and General Practitioners
- Development of systems to request/share information

## **14. Information provision**

Each of the carers support organisations<sup>3</sup> in North Wales provides an information pack to carers when they access their services. These packs vary in content, but all contain information on carer's right to a Carers Needs Assessment and what additional support is available in the area, such as financial help, respite care and short breaks.

In addition in some areas there are information packs specifically for young carers containing age appropriate information on their right and entitlements as young carers.

The 6 Local Authorities in North Wales also provide carers with information outlining their rights and what additional support is available, via information leaflets and their websites.

The Carers strategies (Wales) Measure 2010; guidance document outlines a baseline of information requirements for carers (see appendix 4), and suggests that this can be built upon as every carer will have differing information needs.

A gap analysis of the information provided by the local authorities and third sector carers organisations has indicated that there is range of information available to carers, sometimes this is duplicated and in some areas there are gaps in provision.

This will be addressed by

### **Key Actions: Information provision**

#### **Year 1**

- Exploring the feasibility of developing a core information pack for carers and a similar pack tailored to the information needs of young carers that will address the baseline requirements outlined in Carers Strategies (Wales) Measure 2010 guidance document (see Appendix 4); the aim of this pack will be to ensure all carers are aware of their rights and available support regardless of their age or where they live.

<sup>3</sup> Carers Outreach Service North West Wales (covering Anglesey, Gwynedd, Conwy); North East Wales Information Service (NEWCIS covering Denbighshire & Flintshire); and Wrexham Carers Service

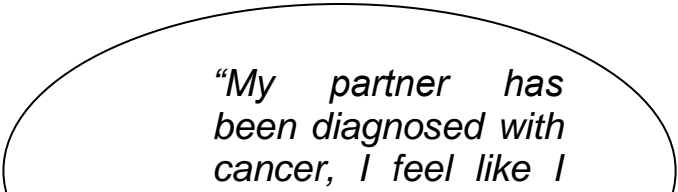


## 14.1 Information Provision by Health Services

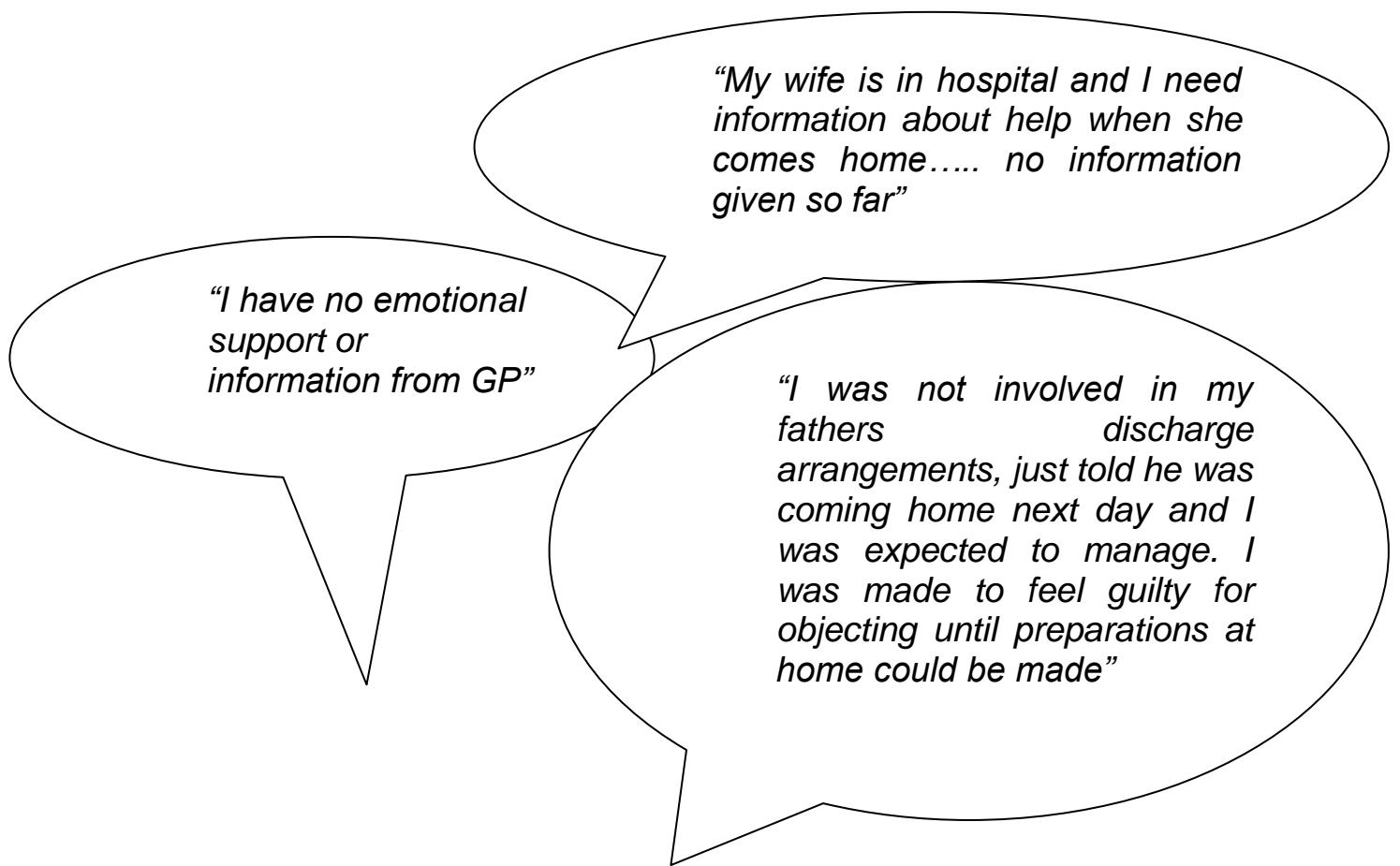
There is specific guidance in the Carers strategies (Wales) Measure 2010 guidance document in relation to hospital discharge and transfers of care and states that as a minimum there should be:

- 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.
- Carers will be given sufficient information that enables them 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. *(Personal and often sensitive information relating to the individual patient about the diagnosis, prognosis and treatment and management both in hospital and afterwards is often withheld from carers; 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).*

In some areas of the Health Board, individual service areas (such as Cancer Services) have produced information for carers or hold a small supply of the local carers support organisations' information pack. However, feedback from carers and service users would indicate that information provision and recognition of carers needs by health service professionals is lacking. (North Wales Carers Leads Strategy Group Survey 2012)



*“My partner has been diagnosed with cancer, I feel like I*



The Health Board will address this by:

### **Key Actions: Information Provision by Health Services**

#### **Year 1**

- Develop web pages on the BCUHB website to provide information packs online and relevant information for carers
- Develop guidance for staff when consent is withheld to share information, to ensure carers are provided with sufficient information as can be shared without breaching patient confidentiality to enable them to care safely.
- Staff training sessions will emphasise the need for staff to involve carers throughout the patient journey.

#### **Year 2**

- Develop an Information Provision Framework for Carers (adults) that will outline the key stages for information provision throughout the patient/carer journey. This framework will cover all forms of information provision (not just written information) and will also include key stages for discussion with carer such as pre-discharge meeting with key health professionals.
- Develop an Information Provision Framework for Young Carers that will outline the key stages for information provision throughout the patient/carer journey. This framework will include the information provided for adult carers, but this will be tailored for age appropriateness and will also include guidance on inappropriate tasks such as administering medications, manual handling etc.
- In addition to BCUHB core Information for carers, service specific information will be produced, for example, information for carers of people with mental health issues re their legislative rights.
- Carers lead to contribute to ongoing work between BCUHB and its partners to develop a single point of access within the local communities. The single point of access will be a valuable resource for information for service users and carers.

### Year 3

- Arrange comprehensive evaluation of information pathway to assess if objectives outlined in section 9 have been met

## 15. Communications and Consultation

One of the key aims of this strategy is to ensure that carers are “*recognised as true partners in care*”. Therefore to make this a reality it is vital that carers are engaged in the care planning process as soon as practicable, before decisions are made and the carers’ knowledge of the person who is being cared for is listened to. This engagement should involve providing and seeking information from carers in a language or medium that they understand and is age appropriate. The Carers Strategies (Wales) Measure 2010: guidance document (Welsh Government 2012) states a minimum requirement that when carers are asked to attend consultation events, organisations must provide sufficient advance notice to enable carer involvement and offer reimbursement of travel and subsistence costs and replacement care costs.

This will be addressed by:

## **Key Actions: Communications and Consultation**

### **Year 1**

- Map current arrangements for carer engagement, to include funding sources for expenses when attending involvement events
- Consult with carers and carer support agencies on preferred methods for carer engagement and feedback
- In partnership with local authorities and third sector organisations agree an infrastructure to allow effective engagement with carers

### **Year 2**

- Develop an involvement framework that ensures all ages and carers from all groups (in particular hard to reach groups) are included.
- Include key points for carer involvement in the Information for Carers Pathway (see section 13.1).

## **16. Training**

A comprehensive training framework is essential to ensure that:

- Carers' issues are mainstreamed into the everyday working practices of NHS and other staff.
- Carers are prepared and supported in their role a comprehensive training framework is essential.

A draft training framework has been produced and this is being considered by the partnership. (see appendix 5)

### **16.1 Staff Training**

At present there is no formal training plan for NHS staff in relation to carers. Some of the local authorities and Third sector organisations provide training for staff and invite NHS staff to attend, however, this is not consistent across North Wales and attendance by NHS staff is patchy. Staff training will be addressed by: (see overleaf)

**Key Actions: Staff Training (see Training Framework Appendix 5)**

### **Year 1**

- Set up a training sub-group of the NWCLSG to further develop the training framework, setting out the priorities for staff training.
- The first priority will be to commission basic Carer Awareness Training for all existing frontline Health Board staff (this will include utilising current training programmes where possible)
- Complete application process to ensure level 1 training is mandatory for all BCUHB staff
- Review Health Board core induction programme, with a view to incorporate carer awareness into the current programme

### **Year 2**

- Identify core competencies for Health Board staff who require Level 2 & 3 training
- Develop lesson plans for Level 2 and 3 training and explore the training methods to be used, such as e-learning, carers' stories, workshops etc.
- Deliver training framework which will be adapted to the level of contact and involvement staff are likely to have with carers in their day to day work

### **Year 3**

- Evaluate training framework

## **16.2 Carers Training**

In order to prepare carers for their role and to ensure they can continue to have a life alongside and beyond the caring role, it is imperative that they are given the relevant skills and knowledge. At present carers in North Wales are offered "Look After Me" courses which focuses on carer wellbeing and is delivered via the Education Programme for Patients (EPP Cymru). Local Authorities in North Wales commission training for carers to be delivered by the Carers Centres and this training may include sessions such as manual handling, first aid, and some condition specific training courses, but there is no formal training programme for carers available.

This will be addressed by:

## **Key Actions: Carers Training**

### **Year 1**

- Consult with carers about their training requirements and preferred learning methods
- Set up Carers Training Group to include carer representation who will advise on course content (this group will also look at young carer training).
- Exploring the feasibility of adding to the “Looking After Me” programme to include core skills such as manual handling, medicines management etc
- Map current carers training programmes for provision and content, with a view to developing standard training programme

### **Year 2**

- Develop and deliver training framework for carers

### **Year 3**

- Evaluate training programme

## **17. Implementation**

To enable successful implementation of this strategy, existing partnerships between, BCULHB, local authorities, private nursing homes and third sector organisation will be utilised and further developed.

The North Wales Carers Strategic Leads Group (NWCSLG) was formed in January 2011. The purpose of this group is to develop an integrated approach across North Wales for engagement with and the development of services for carers of all ages; and to develop an integrated North Wales regional strategy for carers as described in the Carers Strategies (Wales) Measure 2010 guidance document. (see appendix 5).

This group will continue to meet and will act as the partnership working group to take forward the action outlined in this strategy.

The BCULHB Carers Strategies (Wales) Measure2010 Project Board (which includes representation from local authorities and the third sector) will scrutinise the work of the NWCSLG and provide advice and assurance to the

Health Board to ensure that it meets its responsibilities with regard to the Carers Measure.

To ensure that there is engagement from staff in the clinical areas there is an operational group consisting of Health Board staff; the purpose of this group is to provide the specialist knowledge of the clinical areas, disseminate information within the Clinical Programme Groups (CPG), develop CPG specific action plans and advise how the actions within the strategy would be taken forward in each area.

### **17.1 Staff Infrastructure for Implementation**

In order to ensure the required culture change occurs within the Health Board it is important to have a robust infrastructure in place that will ensure carers' needs are taken in to account when planning, reviewing, delivering and evaluating services. BCUHB will facilitate this by:

#### **Key Actions: Staff Infrastructure for Implementation**

##### **Year 1**

- Identify an Executive Lead for delivery of the Carers Strategies (Wales Measure) 2010
- Identify a strategic Lead to ensure development of the Carers Information and Consultation Strategy, and be the key link for liaison with local authorities carers leads and third sector carers organisations
- Employ a Carers Co-ordinator whose main role will be to oversee the operational implementation of the Carers Strategies (Wales Measure) 2010 at BCUHB, with a particular emphasis on raising awareness and staff training
- Identify a non-officer member of the Health Board to be the designated Carers Champion
- Develop role specification for Carers Champion in clinical areas

##### **Year 2**

- Identify Carers Champions within GP surgeries, clinics, hospital wards



Alongside the structures described above, partnerships with local authorities and third sector carers' organisations will be strengthened by conducting joint events wherever possible such as training and consultation events.

## **18. Monitoring**

The following performance measures will be implemented to assess the successful implementation of the strategy (as per the Welsh Government Performance Monitoring framework):-

- % of Carers identified by the partnership
- % of staff within the partnership area who have undertaken training
- % of carers who have been referred for an assessment
- % of carers who take up an assessment

Alongside the Welsh Government Performance Reporting Framework the partnership will also attempt to assess the following outcome measures:

- Carers report that they have been treated by health and social care staff as key partners in the provision of care
- Carers report that they received sufficient information to enable them to undertake their role
- Carers Centres reporting an increase in referrals from health and social care providers

These outcome measures will be monitored by ensuring continuous engagement with carers, regular audits and evaluation of training sessions. The key actions outlined in this strategy will be monitored quarterly by the BCUHB Carers Strategies (Wales) Measure2010 Project Board and the NWCLSG. (See reporting framework Appendix 6)

It is acknowledged that comprehensive monitoring and evaluation of the outcomes for carers will present a challenge to the partnership due to differing information systems;

This will be facilitated by: (see overleaf)

### **Key Actions: Monitoring progress**

#### **Year 1**

- Produce detailed action plan (based on key actions outlined in



## References

Care Council for Wales (2010), **Challenges, possibilities and implications for the workforce in Wales.**

Crossroads Caring for Carers & The Princess Royal Trust for Carers (2008), **At What Cost to Young Carers? An economic assessment of the value of young carers' interventions for young carers affected by parental substance misuse and mental health problems.**

HM Government (2010) **Recognised, valued and supported: next steps Carers Strategy;**[www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)

Powys Carers Service (2009), **“Full of Care: Young Carers in Wales”**

Skills for Care & Skills for Care (2011), **Carers Matter – Everybody’s Business part two: A guide to support carers through staff learning and development,** Leeds.

Social Care Institute for Excellence (2005), **Research Briefing 11: The health and wellbeing of young carers;**  
[www.scie.org.uk/publications/briefing11/index.asp](http://www.scie.org.uk/publications/briefing11/index.asp)

The Princess Royal Trust for Carers (2011) **Always on call, always concerned,** Essex

Welsh Government (2012) **Carers strategies (Wales) Measure 2010: Guidance Issued to Local Health Boards and Local Authorities,** Cardiff.

## **Appendices**

### Legislation

#### **A1.1 Carers Strategies (Wales) Measure 2010**

“The purpose of this Measure is to enable the National Assembly 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-legislation/bus-legislation-meas-cs.htm>

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

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

#### **A1.2 Carers (Recognition and Services) Act 1995**

This was the first piece of legislation that gave rights to carers of all ages who provided 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 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>

#### **A1.3 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>

#### **A1.4 Community Care (Delayed Discharges) Act 2000**

It states that when a Carers 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>

#### **A1.5 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>

### **A1.6 Children Act 1989**

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

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

### **A1.7 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>

### **A1.8 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>

### **A1.9 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>

**A1.10** 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>

### **A1.11 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/businesslegislation-measures-rightsofchildren.htm>

### **A1.12 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 patient's 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>

### **A1.13 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.

**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/unccrarticles/?lang=en>

### **A1.14 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>



## **Carer Information Leaflet – Title to be decided**

### **Who is a Carer?**

A carer is a person, of any age, who provides unpaid support to a family member or friend who could not manage without their help. This could be caring for a relative, partner, or friend who for example is ill, frail, disabled, or has mental health or substance misuse problems. Carers may be juggling paid work with their unpaid caring responsibilities. The term carer should not be confused with a care worker, or care assistant, who receives payment for looking after someone.

### **Taking Care of Yourself**

Think about you!

- Don't be afraid to ask for help.
- Let your GP know that you are a carer; they may be able to arrange additional support for you.
- Arrange to have a Carer's Needs Assessment.
- If you work, tell your employer about your caring role as they may have some measures that can be put in place to help you.
- Make contact with some of the organisations listed in this booklet.
- Try to develop and maintain your life away from being a carer.
- Expert Patient Programme Cymru runs a 'Look after Me' free health and well being course, for anyone looking after someone with a long-term condition please call ; ☎ 01286 674236

### **About this booklet**

You do not need to cope alone. There are many organisations who can offer you practical help and emotional support. This booklet provides contact details for local and national support organisations. If an organisation cannot help you directly they can often put in touch with someone who can.

### **Carer Support**

Local Carers Centres offer a wide range of services aimed at helping you as a carer; whilst taking into account the needs of the person you are caring for. They can also advise on services that your council provides. They are focused on getting you the right advice and support on issues connected with health, emotional support, entitlement, mobility equipment and training. Your local contact number is listed below and their website address is: [www.carers.org](http://www.carers.org)

Denbighshire: North East Wales Carers Information Service:  
[http://www.bungalowsoftware.com/phone\\_symbol85.gif](http://www.bungalowsoftware.com/phone_symbol85.gif) ☎ 01745 331181

Flintshire: North East Wales Carers Information Service:  
☎ 01352 752525

Conwy: Carers Outreach Service:  
☎ 01492 533714

Wrexham: Wrexham Carers Service:  
☎ 01978 318812

Gwynedd: Carers Outreach Service:  
☎ 01248 370797

Anglesey: Carers Outreach Service:  
☎ 01248 722828

## **Carer's Needs Assessment**

If you are providing 'regular and substantial' care for someone, you have the **right** to a **Carer's Needs Assessment**. You don't have to be living with or related to the person you care for. A Carer's Needs Assessment helps to identify the effects that caring has on your life and lets you think about your own needs. It is carried out by Social Services (or on behalf of Social Services by your local carer support centre) who will work with you, to discuss and plan the support they can offer. This may be in the form of respite care, getting help at home, or other support that will help you to maintain your health and wellbeing.

Members of your healthcare team (GP, district nurse, hospital staff etc) can arrange a Carer's Needs Assessment for you. They may ask you if you would like an assessment, but please enquire if you think you would benefit from one. You can also contact your local Social Service direct on:

Denbighshire ☎ 01824 712900

Flintshire ☎ 01352 752525

Wrexham ☎ 01978 292066

Conway ☎ 01492 576333

Gwynedd ☎ 01286 682888

Anglesey ☎ 01248 752752

## Young Carers

If you are a young person caring for someone, there are local organisations that can offer advice, support, short breaks and activities.

Denbighshire Young Carers: ☎ 01745 331222

Flintshire Young Carers: ☎ 01352 755422

Wrexham Young Carers ☎ 01978 264040

Conwy Young Carers ☎ 01492 536091

Gwynedd & Ynys Môn Young Carers ☎ 01248 364614

## Crossroads Care North Wales

Crossroads provides practical care and support. Their core service involves a trained support worker coming into your home to give you a break.

Crossroads is a North Wales wide independent charity, with various local branches. Some of the service may be chargeable. You can contact

Crossroads North Wales Head Office on: ☎ **01492 516435 or 0845 6050115**

## National Organisations

**The Carers Trust** : has designated websites for adults and young carers offering information, advice and support. Both sites host discussion forums, where carers can share their views and exchange information and tips with other carers.

☎ : 08448004361

e-mail: [info@carers.uk](mailto:info@carers.uk)

web site: [www.carers.org](http://www.carers.org)

**Young Carers:** is an online service for young carers run by the Carers Trust.  
[www.youngcarers.net](http://www.youngcarers.net)

**Carers UK:** offers information and advice on all aspects of caring.  
[www.carersuk.org](http://www.carersuk.org)

## Putting Things Right

If you have concerns or feel unhappy with any aspect of the care provided by the NHS, you should feel able to talk to somebody. It is important that the NHS learns from the experiences of patients, friends and families, so that it can try to put things right for you and for others.

As a first step, if you feel able to do so, it is best to talk with someone close to the cause of your concern, such as a doctor, nurse, receptionist or practice manager. It's often possible to sort out the problem straight away.

You may prefer to contact the Health Board's **Concern's Team**:

E-mail: [ConcernsTeam.bcu@wales.nhs.uk](mailto:ConcernsTeam.bcu@wales.nhs.uk)

Post: Concerns Team  
BCUHB  
Ysbyty Gwynedd  
Bangor  
Gwynedd  
LL57 2PW

☎: 01248 384194

## **Betsi Cadwaladr Community Health Council (BCCHC)**

The BCCHC is an independent 'health watch dog' for the NHS in North Wales. It provides information on local health services and offers confidential advice and assistance for people who have concerns or wish to make a complaint about any aspect of the NHS. ☎ 01978 356178

## **Appendix 3 List of carer support agencies**

### Baseline: Carers Information requirements

- Information for carers of people with mental health problem
- Information about the medication given to a patient and where appropriate its 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
- 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 (where appropriate)
  - ✓ The work of the Court of Protection (where appropriate)
  - ✓ Age appropriate support groups
  - ✓ Culturally specific support groups

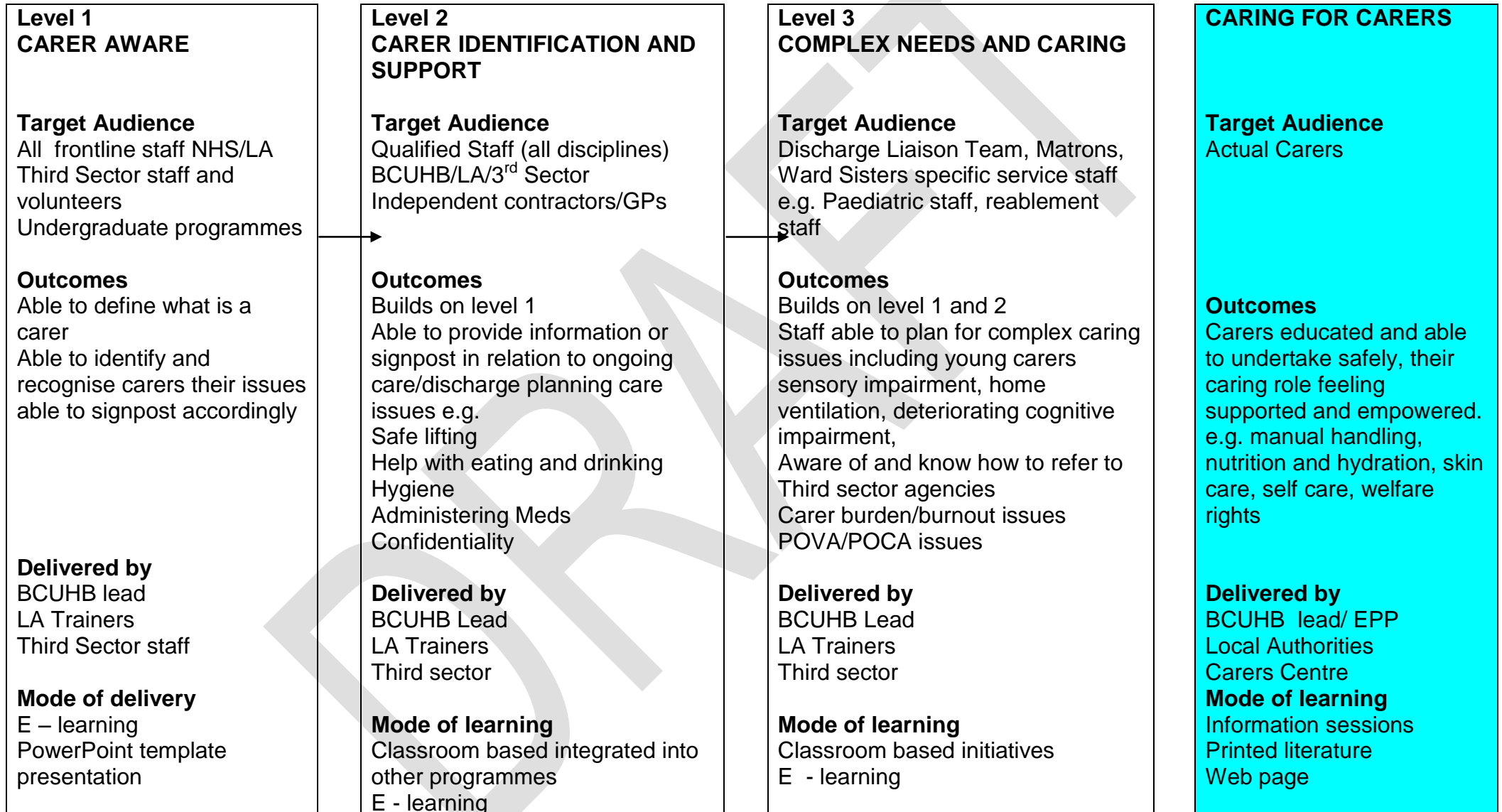
- ✓ Financial advice and support, including information about the availability of financial support through the benefits and tax credits system
  - ✓ Managing the financial and other affairs of cared for persons
  - ✓ Any other information and support available to help support carers in their caring 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
- 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
- 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



## CARERS MEASURE – IDENTIFICATION, INFORMATION, SUPPORT AND CONSULTATION

### CARERS MEASURES - EDUCATIONAL FRAMEWORK<sup>4</sup>



<sup>4</sup> This framework has been adapted from the model used at Cardiff UHB

## NARRATIVE TO ACCOMPANY FRAMEWORK

### Level 1 Carer Aware

This programme would be aimed at all BCUHB staff. Local Authority, third sector staff and volunteers, contractors who have the interest in carers' issues. Outcomes of the programme would be to

- Able to define what is a carer is
- Able to identify and recognise carers issues
- Able to signpost accordingly

The course would be delivered as part of induction/mandatory training, integrated into other training opportunities and within primary care settings. Delivered through e learning, and or a corporately agreed PowerPoint presentation.

### Level 2 Carer Identification and support

This programme would be targeted at Qualified Staff from all disciplines in the Health Board, Third sector managers and relevant Local Authority Staff

Independent contractors/GPs. The aim of the programme would be to

- ensure staff are able to signpost or provide information
- involve carers in relation to ongoing care/discharge planning care issues
- signpost carers to education and training regarding
  - Safe lifting
  - Help with eating and drinking
  - Hygiene
  - Administering Medicines
  - Confidentiality

**Delivered by** BCUHB Lead, LA Trainers, Third sector via Classroom based programmes which have been integrated into existing work streams integrated into other programmes yet to be identified, and via e –learning

### Level 3 Complex needs and caring

This programme would be for staff who are working closely with people who are undertaking complex caring roles. For example caring for those with physical and mental health issues requiring a high level of skill to maintain those cared for in their own environments.

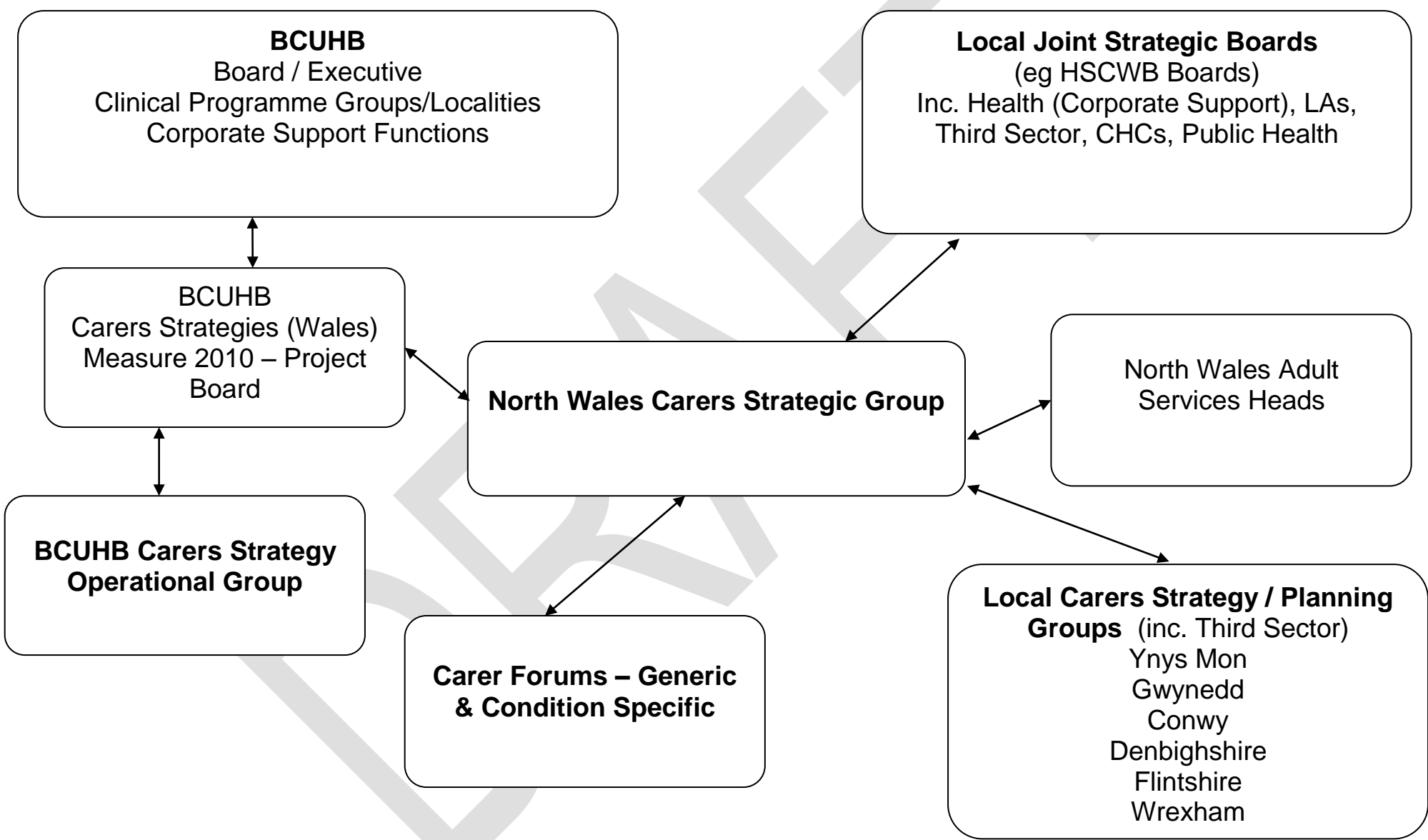
The programme would build on level 1 and 2, and be delivered by BCUHB Lead, LA Trainers, and the Third sector, via Classroom based initiatives and E - learning.

### **CARING FOR CARERS**

Is a programme delivered for carers to enable them to fulfil their caring role to the best of their ability, taking into account their own health issues. The outcomes would be that Carers feel educated and able to undertake safely, their caring role, feel supported and empowered. The content of the programme may include issues such as manual handling, nutrition and hydration, skin care, self care, welfare rights. It would integrate and enhance existing programmes such as the EPP. **Delivered by** BCUHB / EPP, Local Authorities, Carers Centre via Information sessions, Printed literature and development of WebPages.

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Reporting Framework – Appendix 6



To comment on the content of this draft strategy or to seek further information; you can contact Dawn Cooper, Head of Service User Experience. ☎ 01978 727432, or email [dawn.cooper@wales.nhs.uk](mailto:dawn.cooper@wales.nhs.uk)

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