

Gwerthfawrogi Gofalwyr Valuing Carers



Mesur Strategaethau ar gyfer Gofalwyr (Cymru)
Partneriaeth Gofalwyr Abertawe Bro Morgannwg
Strategaeth Gwybodaeth ac Ymgynghori i Ofalwyr • 2013 - 2016

Carers Strategies (Wales) Measure
Abertawe Bro Morgannwg Carers Partnership
Carers Information and Consultation Strategy • 2013 - 2016



Llywodraeth Cymru
Welsh Government



Swansea Carers Centre



BRIDGEND
City Borough Council



GIG
CYMRU
NHS
WALES
Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board



BRIDGEND
CARERS
CENTRE



City and County of Swansea
Dinas a Sir Abertawe



Neath Port Talbot
Carers Service
Support for all Carers



Neath Port Talbot County Borough
Castell-nedd Port Talbot

EXECUTIVE SUMMARY

This Information and Consultation Strategy has been prepared in response to the Welsh Government guidance for the Carers Strategies (Wales) Measure. It recognises that many people, at some time in their lives, will become unpaid Carers, and that new ways of working are required to meet those demands and also the needs of Carers to have a life of their own alongside their caring role.

We know that the numbers of people requiring care and support will rise over time and that people of all ages and backgrounds with increasing complex health and social care needs will require care at home. Therefore, inevitably, the number of unpaid Carers is set to rise across the ABMU area with an increase in the level and intensity of the caring role. Particular focus needs to be given to Young Carers and those from a diverse ethnic background as they have particular needs that require specific advice and support. We also know that Carers are more likely to have health problems of their own, experience higher levels of stress, face financial hardship and social isolation because of the impact of their caring role. This strategy aims to respond to this, by providing better information to Carers and to include them in any decisions made as part of the health and social care needs of their cared for.

Our vision is that all Carers, irrespective of age and situation, should be supported throughout their time as a Carer, given information when they need it and in a way which meets their needs, and be full partners in the planning and provision of care and support for their loved one. This needs to recognise that Carers' needs will change over time, as will their own health status and the level of support they may need to continue in their caring role. Providing this level of flexibility in provision of information and services will be a significant challenge for all services and individuals involved, and will require real culture and attitudinal change across organisations. Accordingly this Strategy and the underpinning action plan concentrates on a wide range of training and awareness raising activities for staff across organisations as being the most powerful and proven way of changing behaviours.

Central to the development of this strategy has been the wide range of engagement activities undertaken with Carers across the ABMU area. A comprehensive programme of awareness raising was rolled out in each Locality of Bridgend, Neath Port Talbot and Swansea so that we could provide staff and Carers with information on the Carers Measure and listen to Carers with regards their issues, concerns and suggestions. Carers were asked about current information provision and support and where this needs to be improved. In addition a series of smaller more intimate sessions took place where health and social care staff attended meetings with Carers to ensure they felt comfortable expressing their views. These processes were extremely valuable and Carers detailed the problems they had experienced and gave helpful suggestions for better and more consistent information and support. As a result, their input has been used to give a clear direction to the development of services and support to Carers over the next three years which are reflected in the action plan later in this document.

This strategy sets out the support we plan to give Carers and is set in the context of good information, advice and support. This will require a commitment to involve everyone, including Carers in decisions about care planning, provision of information and training.

The Partnership intends to continue engaging with Carers on a continuing basis by developing annual action plans which are shared openly with Carers groups and forums and used by them to evaluate progress made by organisations within the Partnership.

<u>CONTENTS</u>	<u>PAGE NUMBER</u>
INTRODUCTION PURPOSE	5
THE CARERS STRATEGIES (WALES) MEASURE EXPLAINED	6
POLICY CONTEXT	7
DEFINITION OF A CARER	9
PROFILE OF CARERS IN ABMU	11
YOUNG CARERS	12
NHS AND LOCAL AUTHORITY ROLES FOR INFORMATION AND CONSULTATION	14
VISION AND AIMS OF THE STRATEGY	19
ACTION PLAN	21
IMPLEMENTATION AND DELIVERY	32
APPENDICES	33

work in partnership to prepare an Information and Consultation Strategy for Carers. As a result, this strategy for the ABM area has been prepared for a three year period to run from 1st April 2013 to 31st March 2016. This will ensure that the significant culture change required to realise the vision for this strategy is realised prior to the new Social Services and Wellbeing (Wales) Bill being enacted. This Strategy should be read in conjunction with the multi-agency Carers Strategies already in place in each of the Local Authority areas. The ABM Information and Consultation Strategy for Carers complements these partnership strategies. The Health Board has the responsibility for publishing this strategy and both the Health Board and Local Authorities have the responsibility for putting it into action. Consequently all four organisations will be formally taking the Strategy through their corporate decision making processes in March / April 2013 to ensure full commitment to the challenging agenda outlined in the Strategy and associated Action Plan.

THE CARERS STRATEGY (WALES) MEASURE EXPLAINED

The purpose of the Carers Measure is to enable the National Assembly of Wales to introduce new legal duties on the NHS and Local Authorities in Wales to work together and in consultation with Carers to prepare, publish and implement a joint Carers Information and Consultation Strategy. The Measure covers all Local Authority and NHS service provision whether these are directly provided or provided by others. The Measure is not targeted at any specific age group it encompasses Carers of all ages, including Young Carers (under the age of 18) and young adult Carers.

The overall intention of the Measure is to improve the lives of Carers in the following key areas:

- ✓ Develop local information strategies that will ensure Carers get "appropriate information and advice"
- ✓ Actively engage with and involve Carers when making decisions about the provision of services to or for Carers or the person cared for

- ✓ Consult about the planning, commissioning and delivery of local services that affect Carers or the people they look after
- ✓ The partnerships will not only be with social services in the local authority but also include other areas, such as housing, education, leisure etc, and the Third and private sectors

The guidance issued by Welsh Government in relation to the Information and Consultation Strategy, specifically seeks to address the following:

- ✓ To ensure that Carers have the right information at the right time to support them in their caring role. The information must be easily accessible, relevant and factually correct for Carers, as well as acknowledging the need for a longer term view of the information needs of Carers.
- ✓ To ensure that statutory agencies properly engage with Carers as partners in the provision of care involving them at all levels in the assessment, delivery and evaluation of care arrangements.

The Health Board and Local Authorities recognise that they cannot achieve the outcomes set out in this strategy without the input and support from the Carers Services established in Bridgend, Neath Port Talbot and Swansea. The role they and Carer representative organisations (e.g. wider carer support organisations, such as Hafal, Cruse, Mind, Alzheimer's society etc) already play in supporting Carers is valued and will be captured in this strategy. It will also be important to develop robust partnership arrangements with Local Service Boards and Local Safeguarding Boards, feeding into the Health Social Care and Wellbeing strategies and local Children and Young People's Plans.

POLICY CONTEXT

Together for Health and the paper *Sustainable Social Services for Wales: A Framework for Action and Refreshing the Carers Strategy for Wales* 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.

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.

Legislation places a duty on Local Authorities to assess Carers' needs and the power to provide services and Direct Payments to Carers. There are three different statutes, which regulate the nature and outcomes of a Carer's Assessment:

- The Carers (Recognition And Services) Act 1995
- The Carers And Disabled Children Act 2000
- The Carers (Equal Opportunities) Act 2004

The key national policy and guidance documents that are drivers in developing and commissioning Carers services are:

- The Carers Strategy for Wales (WAG 2000, revised 2006/7) – a refreshed Carers Strategy will be published by the Welsh Government in April 2013

- Challenging the Myth (“They Look After Their Own”) (WAG 2003)
- Carers Strategies (Wales) Measure 2010 - Regulations and Guidance (2011)
- The Social Services and Well-being (Wales) Bill – published in February 2013

The Mental Health (Wales) Measure 2010 is new legislation introduced by the Welsh Government to help people with mental health problems which also introduces significant new entitlements for their Carers. One of the roles of the new Local Primary Mental Health Support Services, provided jointly by the local authorities and Health Board for this area, is to provide information and advice to individuals and their Carers about treatment and care, including the options available to them, as well as ‘signposting’ them to other sources of support. The Mental Health Measure requires that all people with serious mental health problems who are receiving secondary mental health services must have a care and treatment plan and that all practicable steps are taken to consult with the person’s Carers during the preparation or review of this care plan. Before consulting with Carers the views of the service user must be taken into account, but even where they do not wish the Carer to be consulted the care co-ordinator has discretion to consult if it is judged the right thing to do. Once the care and treatment plan is agreed the Measure requires that a copy is shared with Carers and provides Carers with an entitlement to request a review of the patient’s care and treatment plan if they believe that this is necessary. Making people aware of these entitlements and complying with the requirements of the legislation will contribute to a changed relationship between service providers and Carers in mental health services that should make Carers better informed, supported and assisted in carrying out their caring role.

DEFINITION OF A CARER

A Carer is defined in the Carers Strategies (Wales) Measure as 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.**

This can be someone who has the responsibility for providing or arranging care for someone else who, because of long term conditions, mental illness, disability, old age or substance misuse is not able to care for themselves.

Many Carers live in the same house as the person they care for. Others live nearby and visit regularly. Some live a distance away and visit weekly or monthly. Some provide care for a limited period of time or as part of an informal family support network. Some provide care for more than one person. Caring often impacts on the whole family, not just on one person, and there is no typical Carer.

Carers are individuals who may not see themselves as Carers, but see themselves above all as a parent, child, wife, husband, partner, friend or neighbour. Carers' circumstances vary enormously, as can the type of support they provide, which might be practical, emotional or financial in nature. For example, a Carer supporting someone with a fluctuating mental health problem may provide emotional support. Someone caring for a person who is sick, disabled or frail may provide personal care (i.e. help with washing) and assist with practical tasks.

Taking on a Caring responsibility/role can be a gradual process or it can happen overnight. For example, someone can be plunged into caring when a partner has a car crash or a stroke. Other people move more gradually into a caring role when a relative's health deteriorates over time, which they see as part and parcel of family life. They don't recognise that as the person they look after needs increasingly more support, they are increasingly becoming a Carer. People don't always recognise that they have taken on more caring responsibilities, and are entitled to support in their role as Carer. Equally as important is the need to support Carers who no longer have a caring responsibility. Often those that have lost a loved one following years of caring will need support, bereavement counselling or learning/careers advice.

Many Carers undertake a caring role as well as working, attending school or raising their own families. In addition to caring, Carers may also have to deal with other challenges in their lives, for example, they may have a disability

themselves, they may be a parent Carer or Carer for a person with mental health problems, they may be trying to balance work, studying and caring. The Carer does not have to live with the person they care for to be considered a Carer and the care they provide is unpaid. Carers are a diverse group of people and have different needs and demands on their time. Carers come from all walks of life; they can be any age, any gender, and from any culture.

Black & Minority Ethnic Carers

The Carers Partnership recognises the distinct needs of Black and Minority Ethnic (BME) Carers. The ABM area has a range of different cultures which contribute to the diversity of its population. As a result it is important to support Black and Minority Ethnic Carers in a way which specifically meets their particular needs, which will differ according to their religion and cultural backgrounds as required under the Equality Act.

PROFILE OF CARERS IN ABM AREA

The area served by the ABMU Health Board includes Bridgend, Neath Port Talbot and Swansea Local Authority areas, with a combined population of approximately 540,000 people.

The Table below illustrates the number of Carers in each area across ABM, based on 2001 and 2011 Census data:

Area	Number of Carers 2001	Number of Carers 2011
Bridgend	16,189	17,919
Neath Port Talbot	18,923	20,365

Swansea	28,355	30,349
ABMU (Total)	63,467	68,633

The above table illustrates that Carers represent about **13%** of the ABM population – to put this in context, this is nearly three times the number of people who work for the Health Board. The above also illustrates that the number of Carers in the ABM area has risen by **5166** between 2001 and 2011. For the reasons set out above (p.10), there is likely to be significant under-reporting in the Census returns – the real number of Carers in the ABMU area is likely to be much higher.

YOUNG CARERS

The definition of a **Young Carer** is as follows:

A “Young Carer” is someone aged under 18 who takes responsibility for someone who is ill, disabled, elderly, experiencing mental distress or affected by substance misuse, or substantial responsibility for caring for a sibling.

A child becomes a Young Carer when the level of care and responsibility to the person in need of care becomes inappropriate for that child and may impact on his or her own emotional or physical well-being or educational achievement.

As with adult Carers, there is no typical Young Carer. They may be in a lone-parent household looking after a mother with, for example, multiple sclerosis; they may be in a two-parent family but still be the primary Carer for the sick or disabled parent(s); they may be supporting a brother or sister with special needs. Many young Carers are the primary Carers – the only person providing care – while others share the responsibility with other family members. They have needs which are unique to them as children and young people.

Children and Young People’s human rights are protected through the United Nations Convention on the Rights of a Child (UNCRC). The Welsh Government has adopted these and they are included within national and local guidance as seven ‘Core Aims’ for service provision to Children and Young People. They are as follows:

- Have a flying start in life
- Have a comprehensive range of education and learning opportunities
- Enjoy the best possible health and are free from abuse, victimisation and exploitation
- Have access to play, leisure, sporting and cultural activities
- Are listened to, treated with respect, and have their race and cultural identity recognised
- Have a safe home and a community which supports physical and emotional wellbeing
- Are not disadvantaged by poverty.

There is a distinction between Young Carers and **Young Adult Carers** (aged 18 to 25) and their needs. Both are at a different developmental stage in their lives; one group is legally ‘children’ and the other is legally ‘adults’. Whilst they have experiences and needs that are similar there are also important differences which should be considered, for example, transition to further or higher education or employment with these additional pressures. There are also issues for those that are **Sibling Carers** and the pressures they face whilst caring for a brother or sister if the parent is not able to carry out these duties, or only part of the time.

The following are the numbers of Young Carers in each of the Local Authorities within the ABM area according to 2001 and 2011 Census data (The Young Carer figures for 2011 are yet to be published at the time of writing but will be included once released):

Area	Number of Young Carers (2001)	Number of Young Carers (2011)
Swansea	846	
Neath Port Talbot	604	

Bridgend	509	
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Whilst this strategy refers to Carers in a general sense, i.e. age blind, specific actions for Young Carers are set out in the action plan. The ABM Carers Partnership will work with Young Carers to develop specific information important to them, identify their needs when it comes to consultation and liaise with Young Carer forums on service development. Further, Local Authority education departments will play a key role in implementing specific services to help schools identify and support Young Carers. The ABM Carers Partnership will also work with Substance Misuse and Mental Health teams to develop specific information and signposting for Young Carers who have these specific caring roles.

The Welsh Government will shortly issue an on-line toolkit for professionals in health, social services and education, which will give helpful advice on developing information, resources and services for Young Carers and Young Adult Carers. The ABM Carer Partnership will use this toolkit along with the feedback from engagement to design robust local information and consultation resources for Young Carers.

THE IMPORTANCE OF INFORMATION AND CONSULTATION

The information and advice needed by Carers is wide-ranging and potentially covers all aspects of life. Individual Carers have said that they feel stressed when they have been unable to access information in a timely manner. Well informed Carers are empowered to identify the help they need to support their caring role and their rights as Carers. Approximately 30% of the total number of Carers will be ‘new’ to caring every year. Consequently there is a need to ensure information is always available in a variety of settings, including community, Local Authority, Health and Third Sector services.

The Role of the NHS

Research shows that for most Carers their first point of contact with services is in a primary care setting. Carers need to be identified and provided with information at the earliest contact. This, however, is not a one-off responsibility, as Carers should systematically be consulted and provided with information through all contact with the Health Service both in primary, community services and secondary care. The ABMU Health Board recognises the scale of culture change needed to embed this strategy and has worked with Carers during 2012-13 to extensively engage and consult on their specific needs when it comes to information and consultation.

The key issues highlighted during the engagement process are outlined below. (Further details are included in the Appendices.)

- As part of the roll out of the guidance, there should be education and training sessions provided for all Health and Social care staff, along with GPs and others.
- Focus on frontline staff and those having direct contact with Carers, but also targeting Board members and Executives in order to get senior and political buy-in.
- Accessibility of training is important – recognising staff workload pressures, take the training to staff not taking staff to the training, e.g. online tools and e-learning.
- Shift the focus from Patient to Patient and Carer.
- Ensuring staff are equipped to communicate the caring needs that patients will have as a result of their condition/illness and making sure Carers are aware of these and the implications for them.
- Review of current support available for Carers during a patient's transition through services.
- Explore the range of services that Carers need and identify ways to capture these in information provision, awareness campaigns and advocacy services.
- Review the issues relating to information on identified Carers being shared between agencies. Once identified through a Carers Assessment, the documentation needs to be 'live' and regularly reviewed and updated rather than used as a 'one off'.

- Review all information available to Carers, locally and nationally, and ensure this information is available from a single point of access in each Local Authority area, the information is current and staff are aware of how to signpost Carers to this access point.
- Carers should not have to chase information and it should be available at a much earlier stage.
- Carers need to be referred or signposted to a Carers service at a much earlier stage.
- GPs and their staff need to be able to recognise Carers' stress and have awareness training to support them in this.
- Carers need good information and quality advice regarding welfare benefits e.g. forms and guidance notes written in an accessible form and help from key staff to complete documentation.
- Social workers and other professionals need to be better informed to advise Carers to maximise their welfare benefits.
- Accessing Local Authority information is an issue, e.g. Housing.
- Carers assessments should be an ongoing process and documentation needs to be sent to Carers before the meeting in order to prepare.

As part of the engagement process an Information Mapping exercise was carried out with Carers in order to establish the gaps in provision. Again the following issues were highlighted, with more detail included in the Appendices:

- Need to improve communication of medication effects and dosage implications to Carers – this needs to be emphasised to health professionals, including Pharmacists, Doctors, etc.
- There is particular concern over the information and support available for Carers who care for those with Bi-polar, Dementia, Schizophrenia.
- Standardised information is needed across the three localities as there are currently different levels of information provision. Where one area has a particular resource this could be shared with those that don't. This is particularly the case for Young Carers, where there is a need to update the Welsh Government's training resource for secondary schools and develop new versions for primary schools.

- The timing of the information provision is key as Carers can sometimes feel overwhelmed. Signposting to Carers Services is of paramount importance, with Health and Social care professionals needing a single point for referral within each Local Authority area.
- Generic information source needed for Transport, including community transport schemes, Welsh Ambulance Services Trust, Patient Transport Services and eligibility and information etc. Particular issues include travel to nursing care, respite and parking problems on hospital sites.
- There is inconsistency among professionals with regards referral to Carers services and national support agencies. This needs to be addressed and professionals made aware of their obligation to refer through training and awareness raising.
- Information resources and Directories are available but support to make the right choice and access to advocacy services for help is limited and needs to be developed
- Information needs to be provided on the availability of crisis support and how to access it.
- There is an extensive range of leaflets available from each organisation outlining how to make a complaint, but this can be confusing and Carers are sometimes reluctant to complain due to the perceived risk of losing services.
- Carers need to be signposted to appropriate programmes of support, training and learning, e.g. safe lifting of their cared for person.
- Information at discharge from hospital can be patchy. Discharge Liaison Nurses need to be educated with regards Carers information and Carers Services and documentation used for discharge planning needs to remind staff to consider Carer needs.
- Confidentiality issues are a concern as some professionals are unaware of the rights of Carers and don't communicate key information as it is deemed confidential.

The Role of Local Authorities

Local Authorities have long had the responsibility to support Carers in conjunction with the Third Sector e.g. Carers Services. The support has been led by Social Services but Education has a responsibility to Young Carers and Housing will have a role for all Carers. Local Authorities have a legislative responsibility to carry out Carers assessments and information and consultation play a huge part in this process.

Each of the strategies developed by partners in local authority areas have identified specific issues with regards the provision of information and consultation for Carers and have developed actions, within their strategies, in order to address these. These were identified through a continuous process of engagement with Carers. It is important to note here that these actions have been built on and integrated into this strategy. They include:

- Carers to be seen as 'Partners in Care' by health and social care organisations.
- Carers' support and information is available throughout the area.
- Carers are included in the planning of hospital discharge care arrangements for the cared for person.
- Accessible and relevant information is available for Young Carers.
- Carers information packs developed and GP champions identified
- Carers have a voice in service development and delivery.
- Carers up to date with current information and Carers legislation to help them make informed choices about their caring role.
- Carers can access the right information at the right time.
- Provide information on rights, services and benefits which is accurate, relevant and accessible.
- Ensure that information for Carers is available in a range of languages and formats.
- Provide training and support to equip Carers with the skills and knowledge necessary for them to carry out their caring role.
- All Carers newly referred to Carers' Services to be given information packs including the 'Generic Carers Leaflet', Carers Assessment information, Carers Emergency Card and given a systematic benefits check.

- All Carers on database will receive copies of the Carers Services Newsletter. The newsletter will include information for parent Carers and training available.
- Include Carers Information on NHS Direct Website/Health Challenge Website.
- Ensure that more 'hidden' Carers are aware of Carers Services and other sources of information.
- Provide information to parent Carers and to colleagues who work with parent Carers.
- Promote the use of the Investors in Carers Scheme / RCGP to all GP practices.
- Promote the current range of information available to people from the Black and Minority Ethnic Community.
- Review the information provided to Young Carers through fact sheets and Social Services web pages, e.g. all three Local authorities in the ABM area to have Family Information services.

OUR VISION

Our vision is that all Carers, irrespective of age and situation, should be supported throughout their time as a Carer, given information when they need it and in a way which meets their needs and be full partners in the planning and provision of care and support for those they care for. This needs to recognise that Carers' needs will change over time, as will their own health status and the level of support they may require to continue in their caring role. Providing this level of flexibility in provision of information and services will be a significant challenge for all services and individuals involved, and will require real culture and attitudinal change across organisations. Accordingly this Strategy and the underpinning action plan concentrates on a wide range of training and awareness raising activities for staff across organisations as being the most powerful and proven way of changing behaviors.

AIMS OF THIS STRATEGY

Following the review of the outcomes from the extensive engagement with Carers at events, discussions at Carers Strategy group and the information mapping exercise, the following overarching aims have been developed:

- A1) All relevant information is available to Carers of all ages in the ABMU area. The information is up-to-date and available at the right time and in the right place.
- A2) All staff in health (including GPs) and social care that come into contact with Carers can identify Carers, recognise their needs, provide them with appropriate information and signpost them to relevant services.
- A3) Carers are engaged and consulted regarding any decisions made during their journey through health and social care services that affect them or the person they care for.
- A4) Once identified, all eligible Carers are offered a Carers Assessment (and assessed as Child in Need if a Young Carer), ensuring their needs are addressed. The assessment is not a one-off event, but should be reviewed regularly and the continuing support for the Carer should be monitored.
- A5) A Carers Partnership exists between ABMU Health Board, Bridgend County Borough Council, Neath Port Talbot County Borough Council, City and County of Swansea, Carers Services in each area, Third Sector organisations and Carers themselves so that a commitment is made to the ongoing joint working to improve the lives of Carers in the ABM area.

THE ACTIONS WE WILL TAKE TO ACHIEVE OUR AIMS

A1) All relevant information is available to Carers of all ages in the ABMU area. The information is up-to-date and available at the right time and in the right place.

ACTION	EXPECTED OUTCOME	LEAD	YEAR 1,2 OR 3
<p>1. (a) Produce and make available relevant information for Carers, with a particular focus on ‘gap’ areas.</p>	<p>Carers report that current gaps in provision of and access to information, based on extensive information mapping exercise, are addressed, eg. ADHD, Bi-polar, dementia, and schizophrenia and specific needs of former Carers no longer in a caring role.</p>	<p>ABMU Health Board Local Authorities Carers Services</p>	<p>Year 1</p>
<p>1.(b) In partnership with organisations such as Swansea Bay Race Equality Council, review information supplied for Black and Minority Ethnic Carers</p>	<p>BME Carers and those working with BME Carers report improvement in the range of information provided (as part of the work to implement Equality and Diversity Strategies)</p>	<p>ABMU Health Board Local Authorities Carers Services</p>	<p>Year 1</p>
<p>2. In partnership with Department for Works and Pensions (DWP) and other agencies such as CAB, Local Authorities will work with Carers to improve access to benefit related information, with a specific focus on:</p> <ul style="list-style-type: none"> - Welfare Reforms / Benefits advice - access to advocacy 	<p>Carers affected by the UK Government’s Welfare Reform are better informed of the potential implications on their circumstances and how best to access advocacy support</p>	<p>Local Authorities</p>	<p>Year 1</p>
<p>3. Engage with Carers regarding the most suitable times and locations for information to be available in health, local authorities and Third Sector organizations, and plan distribution accordingly</p>	<p>Carers can access the information they need at key locations in health and social care and Third Sector organisations, e.g. GP practice, hospital receptions, libraries etc. This will also need to include Young Carer and Black and Minority Ethnic Carer access points, e.g. Youth Clubs, Schools, Mosques etc.</p> <p>Carers are signposted to relevant information and services at key stages and times during their journey through health and social care, e.g. diagnosis, referral,</p>	<p>GP Practice Champions ABMU Health Board Local Authorities</p>	<p>Year 1</p>

	treatment, home care planning etc		
4. Develop an ABMU information pack for Carers which is jargon free/easy read, recognising there will need to be some local variation	Carers are provided with an information pack when they need it (e.g. could be some time after their loved one's episode of care) by health and local authority professionals, Carers service staff and other professionals.	ABMU Health Board Local Authorities Carers Services	Year 2
5. Produce and make available information for Carers regarding entitlements to be consulted and involved in the development and review of care and treatment plans under Part 2 of the Mental Health (Wales) Measure 2010.	Carers are more aware of their rights under the Mental Health (Wales) Measure 2010 which will contribute to better involvement in the care and treatment planning process.	ABMU Health Board Local Authorities	Year 1
6. Develop a Single Point of Access for Carers to access all the Information they need, by further enhancing the role of local Carers services as the portal for this.	Carers are able to access all the information they need by visiting one website or making one phone call, <i>in addition to</i> the information packs	ABMU Health Board Local Authorities	Year 2 and 3
YOUNG CARER ACTION 1 Undertake a specific exercise in partnership with Young Carers and Young Carers Forums to identify their information needs, building on the mapping exercise undertaken for adult Carers	Young Carers receive improved support through appropriate information and packs produced by agencies/organisations.	Local Health Board Local Authorities	Year 1
YOUNG CARER ACTION 2 Based on the exercise above, produce information packs including the information Young Carers want and need	Young Carers are able to receive the most appropriate information for their needs; information will link with Family Information Services in each Local Authority along with Education departments and Local Safeguarding Children's Boards. Information packs	Local Health Board Local Authorities Carers Services	Year 1

	will be innovative and easily accessible using Easy Read and jargon free content.		
YOUNG CARER ACTION 3 Information pack to be reviewed for quality and relevance after Year 1 and the content updated. Implement mechanisms in to ensure this is undertaken on a regular basis and information provision is sustainable after the 3 rd year of the strategy	Young Carers have information available to them which is up to date, remains relevant and the provision is sustainable beyond the 3 year strategy period.	Local Health Board Local Authorities Carers Services	Year 2 and 3
A2) All staff in health and social care (including GPs) that come into contact with Carers can identify Carers, recognise their needs, provide them with appropriate information and signpost them to relevant services			
ACTION	EXPECTED OUTCOME	LEAD	YEAR 1,2 OR 3
1. A Carers Coordinator will be appointed within ABM in order to ensure culture change activities are developed and coordinated across the 3 localities, e.g. training, awareness raising etc	Better information provision and proper engagement with Carers, to achieve cultural change, will be further enhanced by a co-ordinator with a specific focus on driving forward the actions developed by the partnership, follow up specific areas requiring greater attention, and provide a key point of contact.	ABMU Health Board	3 Years
2. Provide access to an Online Carers Training Tool (Carer Aware) for Health and Social care staff, and promoted access to organisations commissioned by the Health Board and Local Authorities A tiered approach to training will be implemented, with different levels of achievement expected based on level of contact with Carers, e.g. ward staff will	The online tool will help to improve the skills that Health and Social Care staff will have to identify, support and signpost Carers to access the right information and services.	ABMU Health Board Local Authorities	Year 1 (ongoing)

<p>be expected to complete all 3 modules of Carer Aware and certain administrative staff expected to achieve level 1.</p> <p>Where appropriate Carers will be invited to provide aspects of this training themselves as experts in their own right, e.g. at Staff induction programmes, ward training and social care training.</p> <p>Provide additional training as part of the existing training mechanisms in health and local authorities</p>	<p>Involvement of Carers ensures continued relevance to and improved engagement with the audience</p> <p>Additional training programmes will further develop knowledge and skills in specialist subject areas, build on the skills gained through the online tool, and cover requirements for those not able to access online training easily.</p>		
<p>3. A general awareness campaign will be carried out across all GP practices in ABMU, highlighting the needs of Carers across primary care, tackling issues identified through consultation such as :</p> <ul style="list-style-type: none"> - some hidden Carers who do not understand the term Carer - asking Carers if they 'look after someone' rather than 'are you a Carer?' 	<p>GP practice staff are more aware of the needs of Carers, e.g. following up on 'Are You a Carer?' forms.</p>	<p>ABMU Health Board Local Authorities</p>	<p>Year 1</p>
<p>4. The RCGP toolkit will be rolled out in 5 GP practices in each Locality and then rolled out to all practices within the timescales of the strategy (10 practices Year 2 and all remaining practices in Year</p>	<p>GPs are able to identify Carers earlier, offering them the information, support and signposting they need. Carers report a good or improved experience when visiting their GP in relation to their own health and improved level of consultation concerning care of the</p>	<p>ABMU Health Board</p>	<p>Year 1 (roll out to remaining practices in years 2</p>

3) This will include the identification of Carers Champions	cared for, where appropriate.		and 3)
5. We will ensure that all staff undertaking the care co-ordinator role are provided with training on care and treatment planning under the Mental Health Measure, including the need to engage and consult Carers.	That Carers of people with serious mental health problems receiving secondary mental health services are involved as much a possible in the development and review of care and treatment plans.	ABMU Health Board Local Authorities	Year 1
6. Carers will be supported at work; and we will investigate the possibility of this approach being used by other organisations in the ABMU area to inform their own approach to Carers in the workforce.	Carers who work in Health and Local Authorities are supported to ensure they achieve work / life balance. Those with significant caring responsibilities wishing to remain in employment or return to employment receive relevant information.	Initially: ABMU Health Board Local Authorities	Year 2
7a) Carers' Partnership will work with Carers to determine further training needs, with aim of identifying Expert Carers b) Carers will be provided with Training so they have the opportunity to improve their skills, e.g. manual handling, medicines management etc. c) Review current Carer training in order to identify best practice and highlight any gaps	Carers are able to access training to develop the necessary skills to perform their caring role in a safe manner.	ABMU Health Board Local Authorities Carers Services	Year 2
8a). Work will be carried out to build on the number of Carer Champions identified during training and awareness programmes in health and local authorities organisations (including GP	Carers Champions are identified to raise the profile of Carers and to disseminate Carer-related information	ABMU Health Board Local Authorities Carers Services	Year 3

<p>practices).</p> <p>b) Provide further training to specific staff members to provide them with the skills to train others and disseminate new information to colleagues, teams and partner providers in relation to Carers</p> <p>c) The Carers Partnership will work specifically with GP practices to ensure they have the tools to support Carers and signpost them to the correct advice, advocacy and information.</p>	<p>Those specific staff members identified have received further training, ensuring skills and information are more effectively disseminated to a wider range of colleagues, teams and partner providers.</p> <p>GP practices, as key partners in achieving cultural change, feel supported by the partnership to develop and refine the support provided to Carers.</p>		
<p>YOUNG CARER ACTION 1</p> <p>A specific training package will be purchased in order to provide staff with targeted training on the needs of Young Carers. This package will be rolled out at the same time as the general Carer Aware training provision.</p>	<p>Health and Social Care staff have improved skills to identify, support and signpost Carers to access the right information and services.</p>	<p>Local Health Board</p>	<p>Year 1</p>
<p>YOUNG CARER ACTION 2</p> <p>Work will be undertaken through the Carers Partnership with Young Carers to scope their training needs and develop specific ways to help them cope with their caring role, offering them help and support</p>	<p>Improved resilience / coping ability of Young Carers resulting from this exercise will allow planning of any additional training requirements necessary and specific to Young Carers.</p>	<p>Local Health Board Local Authorities</p>	<p>Year 1</p>
<p>YOUNG CARER ACTION 3</p> <p>Work will be undertaken to better identify Young Carers by schools and teachers, offering support, advice and</p>	<p>Young Carers are receiving advice and being signposted to relevant organisations that specifically support Young Carers.</p>	<p>Local Authorities</p>	<p>Year 2 and 3</p>

<p>signposted to relevant organisations that specialise in Young Carers.</p> <p>This will also specifically address identification of Sibling Carers, who provide care for their brother or sister, which can impact on their education and leisure.</p>			
<p>A3) Carers are engaged and consulted regarding any decisions made during their journey through health and social care services that affect them or the person they care for</p>			
ACTION	EXPECTED OUTCOME	LEAD	YEAR 1,2 OR 3
<p>1. Develop Carer pathways to include the Clinical and social services assessment documentation that will be used to ensure consultation with Carers is emphasised at every stage in their journey through health and social care, e.g. referral forms, Unified Assessment and discharge planning documentation etc</p>	<p>Carers are better engaged and consulted with regards decisions on the care for their cared for. This will include arrangements for hospital discharge and ongoing support in the community or in their own homes. Carers are given basic advice on the needs of the cared for when leaving care and then further training offered shortly afterwards.</p>	<p>ABMU Health Board Local Authorities</p>	<p>Year 1</p>
<p>2. A comprehensive resource pack will be developed and issued to relevant staff to inform them what information can be shared with Carers regarding those that they care for. This will include fact sheets, online resources and local reference and advice points</p>	<p>Confidentiality issues are addressed and Carers are given the correct information about their cared for's condition, situation and capacity. All staff are clear about their obligation to share information when legally appropriate to do so. This will also include information during transition from child to adult.</p>	<p>ABMU Health Board Local Authorities</p>	<p>Year 1</p>
<p>3. Develop a single point of access for appropriate information and support for</p>	<p>Carers are given access to the right information and support <u>before</u> their cared for goes into Crisis. Carers</p>	<p>ABMU Health Board</p>	<p>Year 2</p>

those Carers experiencing crisis including 'Coping Plans' for staff to provide to those nearing crisis, e.g. Mental Health Carers	will receive information on all the services available, with explanations around access criteria.	Local Authorities	
4. Compliance with above documentation is regularly audited to ensure health and social care staff engage and consult Carers.	Carers needs are identified and addressed.	ABMU Health Board Local Authorities	Year 2 and 3
5. Conduct Carers' Surveys following contact with health and social care services to ensure Carers experience is captured and test staff compliance.	Carers feel more engaged in the development of health and social care services. This will also include complaint resolution. Survey results will be available to develop future necessary actions to improve services in the future.	ABMU Health Board Local Authorities	Year 3
YOUNG CARER ACTION 1 The Carers Partnership will work with Young Carers Forums to survey Young Carers (and Young Adult Carers) about their experiences of health and local authority services.	Young Carers are able to comment on the services they receive, good or bad.	ABMU Health Board Local Authorities Young Carer Forums Carer Services	Year 1
YOUNG CARER ACTION 2 The above Hospital and social care documentation will be reviewed to highlight the needs of Young Carers, especially considering those who care for someone with a substance misuse issue or mental health problems. Specific signposting materials will be developed for accessing Carer support for those caring for someone with	Young Carers will be given specific appropriate support, based on the Unified Assessment process. Staff will feel able to highlight their needs and signpost to the relevant advocacy services. Young Carers caring for someone with substance misuse or mental health problems will feel better supported	ABMU Health Board Local Authorities	Year 2

substance misuse and mental health problems.			
YOUNG CARER ACTION 3 The Carers Partnership will work with the Regional Advocacy initiative to improve access to information and support for advocacy services.	Young Carers are able to access improved support and information when accessing hospital and social care services for their cared for.	ABMU Health Board Local Authorities	Year 2 and 3
A4) Once identified, all eligible Carers are offered a Carers Assessment (and assessed as Child in Need if a Young Carer), ensuring their needs are addressed. The assessment is not a one-off event, but should be reviewed regularly and the continuing support for the Carer should be monitored.			
ACTION	EXPECTED OUTCOME	LEAD	YEAR 1,2 OR 3
1. Provide training through the Carer Aware package to social care staff to enable Carers who may be eligible for an assessment to be identified accurately.	Carers and staff are aware of and understand Carers rights regarding Carers Assessments. Carers and staff understand what a Carers Assessment involves and the option to request one at a later date.	Local Authorities	Year 1
2. Social Work staff will continue to offer Carers Assessments to Carers who are eligible and for those that don't offer comprehensive signposting and information on local services	All relevant staff are aware of the importance, the duty and the value of offering eligible Carers assessments. All eligible Carers who are in contact with Adult Social Worker Teams are offered a Carers Assessment, including Parent Carers. Staff have available signposting and support information and offer this to Carers where assessment not undertaken.	Local Authorities	Year 1 (and ongoing)
3. Staff will assist Carers to access an assessment and provide comprehensive	Carers will be better supported during their assessment and are able to make an informed choice	Local Authorities ABMU Health	Year 2

information and support, making sure a Carers Assessment Checklist is available	when accepting and declining an assessment. Carers will therefore feel supported through this process with signposting information and support networks offered	Board	
4. The Carer's Assessment will be a live document, revisited and reviewed regularly to ensure Carers are receiving the level of support needed.	All those that have had a Carers Assessment are reviewed and their needs re-assessed.	Local Authorities	Year 3
YOUNG CARER ACTION 1 Staff will be given training via the Young Carer Aware training package to ensure they recognise and can identify Young Carers, ensuring they are assessed under the Framework for the assessment of Children in Need	Staff are confident in identifying and recognising Young Carer needs and are able to signpost them to relevant information and support networks.	Local Authorities ABMU Health Board	Year 1
YOUNG CARER ACTION 2 Undertake training for Social Work teams to ensure those Young Carers who are eligible are offered a Carers assessment	Young Carers' specific needs are assessed and the relevant support offered to them and their families	Local Authorities	Year 2
YOUNG CARER ACTION 3 Undertake a review to ensure all Young Carers assessments are monitored regularly.	All Young Carers are receiving the best level of support available through proper assessment, information provision and consultation.	Local Authorities	Year 3
A5) A Carers Partnership exists between ABMU Health Board, Bridgend County Borough Council, Neath Port Talbot County Borough Council, City and County of Swansea, Carers Services in each area, Third Sector organisations and Carers themselves so that a commitment is made to the ongoing joint working to improve the lives of Carers in the			

ABM area.			
ACTION	EXPECTED OUTCOME	LEAD	YEAR 1,2 OR 3
1. A Compact is signed up to by ABMUHB, the three Local Authorities, the three Carers Services and the Third Sector network to ensure a partnership approach to addressing Carers needs.	Carers feel confident that health, social care and voluntary sector organisations are working together to improve their lives.	ABMU Carers Partnership	Year 1
2. Regular events are held for Carers (from big events to coffee mornings) to meet with health and social care staff to raise issues, share information and engage on service delivery.	Carers can attend regular events and meetings to express their views, share information and relieve isolation.	ABMU Carers Partnership	Years 1, 2 and 3
YOUNG CARER ACTION 1 Ensure that the Compact above will make specific commitments to work in partnership with Young Carers.	Young Carers are given the opportunity to attend events specific to them, where they can make friends, have respite from their cared for and gain advice and support from professionals	ABMU Carers Partnership	Year 1, 2 and 3
YOUNG CARER ACTION 2 The Carers Partnership will develop an ongoing commitment to work with Young Carers Forums to ensure their views and feedback informs service development.	Young Carers are able to feedback their concerns and inform service development in an environment they feel most comfortable.	ABMU Health Board Local Authorities	Year 1, 2 and 3

IMPLEMENTATION AND DELIVERY

Implementation of this Information and Consultation Strategy will require joint action by the Health Board, Local Authorities and Carers services, together with ongoing engagement with Carers. The Carers Strategy Group will be responsible for overseeing the delivery of the Strategy and monitoring performance. An Outcomes Framework is being developed at a national level between all the Carers Partnerships across Wales and will result in a robust set of performance measures that will aim to capture meaningful information on whether the lives of Carers have improved. Nevertheless, the following will be important aspects in delivering the Strategy and ensuring we achieve our aims:

Annual Action Plans

The Information and Consultation Strategy is not a fixed and final plan but will provide the overarching framework which sets out what will be taken forward over the next three years. The action plan included in this strategy gives an overall picture of the type of action needed over the three year period but detailed annual action plans will be developed in partnership with Carers. The annual action plans will also set out specific actions for Young Carers.

Monitoring

Progress on the annual action plans will be monitored quarterly by the Carers Strategy Group and feedback will also be given regularly at Carers Action Groups / Forums in each of the local authority areas. Progress will also be communicated to Carers at regular events and informal feedback sessions. Adult and Young Carers will also be given the opportunity to review compliance with the strategy at the regular events and coffee mornings planned across the ABMU area.

Appendix 1

CARERS STRATEGIES IN BRIDGEND, NEATH PORT TALBOT AND SWANSEA

The Local Authorities in Bridgend, Neath Port Talbot and Swansea, for many years, have developed Carers Strategies in partnership with Carers, Third Sector partners and other government departments such as the pension service and Job Centre Plus. These strategies have been used to scope, develop and implement vital services for the Carers in those areas. Each area has a Carers Action Group / Forum that meets regularly to monitor the strategies and their associated action plans. The action plans seek to highlight the issues facing Carers locally and therefore put things in place to address those issues. The current priorities within these action plans are as follows:

Swansea

- All eligible Carers will be offered an assessment of their own needs.
- More effective hospital discharge procedures and community support.
- Carers of people who are eligible for community care services to be able to benefit from a break from their caring role.
- Carers' needs reflected more significantly in local strategies with a commitment to ongoing involvement and consultation of Carers.
- Increase support for parent Carers of children and young people.
- Carers to be able to access training pertinent to their caring role.
- To have an easily identifiable Carers' Centre that provides support, welfare benefit support and advice, information and the services of a professional counsellor.
- Increasing access to leisure opportunities for Carers.
- Support for Carers wanting to return to work and support for Carers who are in work.
- Improved support to black, minority ethnic Carers, with statutory staff more aware of cultural issues.

- Young Carers should have their needs recognised and be supported to access assessment, so they can be supported in their caring role.
- Raise awareness of Young Carers issues and improve their access to leisure opportunities.

Neath Port Talbot

- Residents of Neath Port Talbot who are providing unpaid care and support recognise that they are a Carer and can choose to access 'Carer' services.
- Increase the number of Carers who make an informed choice to take up the offer of a Carers Assessment.
- Carers in Neath Port Talbot are listened to, treated with respect and receive recognition for the important contribution they make.
- Carers will be supported to stay as mentally and physically well as possible.
- There are a range of support services available to Carers and clients which aim to meet identified needs.
- Young Carers will be supported, protected from inappropriate levels of caring, and have the support they need to learn, develop and enjoy a positive childhood.
- To ensure Carers obtain maximum financial advantage related to their individual circumstances and are supported to remain economically active and have opportunities for accessing training, education and employment.

Bridgend

- All identified Carers to have improved access to support in an emergency.
- Encourage Carers to identify themselves as Carers.
- To develop and promote a range of available services to enable Carers to continue in their caring role.
- Carers have a voice in service development and delivery.
- Carers issues are positively and widely published across the community.
- The development of a Carers register across the ABMU Health Board network.

- Ensure that young Carers in Bridgend County Borough are not required to provide 'inappropriate care' for the person they care for.
- Positively raise awareness of the work and number of Young Carers in Bridgend in schools.
- The voice of young Carers is heard and informs service development across the partnership.
- Improve the take up of Direct Payment by 20% by those Carers who are eligible.

Appendix 2

Information Mapping Exercise

In June 2012, a short mapping exercise was conducted in each Locality in order to identify good practice with regards information provision to Carers. This exercise was also aimed at identifying gaps in provision so these could be highlighted for action. The mapping exercise was based on the information requirements included in the Carers Measure guidance.

In summary, there are pockets of good provision of information, with Carers Centres seen as the pivotal focus points for Carers being able to access this information. However, there are issues with information given on medicines dosage for the cared for, those that are new to caring and don't know what services are available and issues with standardisation of information across the three areas in ABMU. A detailed copy of the mapping exercise is outlined below. This mapping exercise will therefore inform the overall action for this strategy

issues with standardisation of information across the three areas in ABMU. A detailed copy of the mapping exercise is outlined below. This mapping exercise will therefore inform the overall action for this strategy.

Review of Carers Information Mapping	
1. Information is given to Carers of people with mental health problems on their specific legislative rights	Good provision of MH information in NEATH PORT TALBOT and Swansea. Conflicting views in Bridgend – Carers drop in session confirmed information is poor, but Carers rep confirmed good provision – needs to be investigated further.
2. Information is provided about the medication given to an individual and where appropriate the potential side effects;	Need to improve communication of medication effects and dosage implications to Carers – these needs to be emphasised to health

professionals, including Pharmacists, Doctors, etc.

- 3. general or specific information is given 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)**

Improvements needed to ensure medication and treatment discussions include the Carer. Health and social services staff need access to information pack that can be given to Carers. Confusion can arise when not being able see the same GP. There is particular concern over the information and support available for Carers who care for those with Bi-polar, Dementia, Schizophrenia

- 4. Information is provided that assists children and young people to avoid taking on inappropriate levels of caring and signposts them to sources of assistance**

NEATH PORT TALBOT have young Carers booklet currently being printed. Swansea has a leaflet and Website. Bridgend do not have access to these resources – need to standardise provision. Access to information pack for Schools is important and currently lacking – need to update WG Secondary Schools pack and develop new for primary schools (Young Carers need to be involved in the development of these packs). All information in packs, website and leaflets need to address the issue of ‘avoiding’ caring at an early age.

- 5. Accessible information and signposting to information is given on the availability, entitlement to and**

sources of local and national support including:

- a) short breaks / respite care
- b) Carers needs assessments
- c) Direct Payments
- d) housing support
- e) independent advocacy
- f) counselling including bereavement support
- g) guardianship if appropriate
- h) the work of the Court of Protection if appropriate
- i) age appropriate support groups
- j) culturally specific support groups
- k) financial advice and support, including information about the availability of financial support through the benefits and tax credits system
- l) managing the financial and other affairs of cared for persons

<p>m) any other information and support available to help support Carers in their caring role</p> <p>Carers Centres provide the majority of this information in all Localities. The timing of the information provision is key as Carers can sometimes feel overwhelmed. Signposting to Carers Centres is of paramount importance, with Health and social care professionals needing a single point for referral.</p>
<p>6. Information, or signposting to information and advice is given on employment provisions, including flexible working</p> <p>Again all three Carers Centres / Service have excellent advice services but newly identified Carers need to be signposted to their services. Work needs to be done with large employers in ABMU area to ensure HR policies reflect Carers rights</p>
<p>7. Information is provided on:</p> <ul style="list-style-type: none"> a) the range of Social Services functions available to Carers and cared-for persons b) care planning for the person cared for c) medicines management, safe handling, moving and lifting and other matters relating to the care of the person cared for <p>Information is available but again this needs to be standardised across the ABMU area and available from a central source. Particular issues include access to manual handling and occupational therapy advice</p>
<p>8. 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</p> <p>Generic information source needed for Transport, including community transport schemes, WAST PCS service and eligibility and information etc. Particular issues include travel to nursing care respite and parking problems on hospital sites</p>
<p>9. Information and support on aids and adaptations including Telecare and Telehealth services and the waiting times one can expect for such items</p> <p>Need to gather information from each Local Authority and ABMU on availability and waiting times for Telecare / Telehealth. Information needs to include the benefits of using technology. NEATH PORT TALBOT already provide leaflet on Telecare so this could be adapted for other areas.</p>
<p>10. Information on the regulation and inspection of services, i.e. the work of Healthcare Inspectorate Wales and the Care and Social Services</p>

Inspectorate for Wales

Information is available in factsheets provided by CSSIW and HIW but access and awareness of these is limited. These need to be provided from a central source

11. Signpost Carers on to a local carer support agency and to appropriate national organisations supporting patients, users and Carers for specific conditions

There is inconsistency among professionals with regards referral to Carers services and national support agencies. This needs to be addressed and professionals made aware of their obligation to refer.

12. Information given on hospital admission avoidance

Poor awareness of admission avoidance across the three areas. Information is available in Swansea with regards patients relapse avoidance but is not standardised. Signposting to peer support groups needs to be strengthened. Community Networks and CRTs need to address this

13. 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 resources and Directories are available but support to make the right choice and access to advocacy services for help is limited and needs to be developed. This is sometimes a capacity issue for Carers Centres/Services.

14. Information on the availability of crisis support and how to access it

Plethora of information available from different sources so again needs to be centralised. Bridgend highlighted the use of the Carers Emergency Card as useful. Can these be distributed across ABMU?

15. Information on the availability of re-ablement and intermediate care

Information is available but only on specific elements of reablement. There needs to be an up-to-date resource of all the information

on these services and available centrally.
<p>16. Help is given to 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) This information is available from Carers Centres/ Services via their information packs (NEATH PORT TALBOT and Bridgend) and newsletters (Swansea). Need to promote the role of the Carers Centres / Services across ABMU – not only among health and social care staff but general public too</p>
<p>17. Information on the Organization's complaints procedures and those of the Public Service Ombudsman for Wales</p> <p>Extensive range of leaflets available from each organisation's complaints procedures, but this can be confusing and Carers sometimes reluctant to complain due to risk of losing service. A standardised 'easy to follow' process needs to be developed depending on which service the Carer is receiving</p>
<p>18. Information is provided for Carers who wish to stop their caring role Most Carers are not aware of the option to stop caring and accept this. However, support is needed to help them make this decision and be aware of the options available to them. Swansea Carers Centre provides specific advice on this which could be standardised across ABMU</p>
<p>19. Signposting to appropriate programmes of support and learning, these may include training on:</p> <ul style="list-style-type: none"> a) safe lifting, moving and handling b) medicines management including the safe administration of medication to the cared or person c) relevant nursing skills d) use of aids and adaptations e) continence care f) stress management g) help with eating and drinking h) dealing with the behavioural aspects of the cared for person i) helping Carers to look after themselves <p>Whilst there is awareness that Carers can access these services there is no way of monitoring how professionals are signposting Carers to these services. There needs to be a robust system in place to monitor referrals, so that Carers Centres / Services can track who has been referred to which service</p>
20 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

Information at Discharge can be patchy. Discharge Liaison Nurses need to be educated with regards Carers information and Carers Centres. Information on medication is particularly important here and signposting Young Carers to support in the community. Patient Experience Unit in ABMU is developing bed-side guides for those in hospital which aims to include information for Carers.

21. personal and often sensitive information relating to the individual patient about the diagnosis, prognosis and treatment and

management both in hospital and afterwards

Confidentiality issues are a concern here as some professionals are unaware of the rights of Carers and don't communicate key information as it's deemed sensitive. Need to address this as some professionals are risk averse. One Carer in Bridgend had to get married in order to obtain information!!!!!!

22. 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.

Groups felt this question summarised a lot of the above and was important as an overarching theme throughout activities.

Professionals need to treat Carers as another member of the caring team when communicating information. Bridgend Carers Centre will soon offer a Befriending service which will offer a 'buddy' concept. This could be developed across ABMU?

Appendix 3

Carers Measure Awareness Event

In December 2011 an event was held in Neath Port Talbot which invited Carers from across the ABMU area to give an account of their experiences. A number of high profile speakers also attended to provide support for this initiative, including Sarah Austin (Author of the Measure Guidance), Hywel Francis (MP) and Dr Ed Roberts (ABMU Vice Chairman). The event was very successful with over 80 staff members present from primary care, community nursing and social services.

Following the event a workshop took place to highlight the issues facing Carers in the ABMU area, identify the gaps in service provision and summarise the priorities for taking forward. These are as follows:

- Clear guidelines are needed for identifying all Carers, ensuring consistent approach across all agencies and professions. Early identification is important and should be based on a 'common sense' approach, recognising a sign for Help! As part of the roll out of the guidelines, there should be education and training sessions provided for all Health and Social care staff, along with GPs and others. The education and training should include the following:
 - Involvement needed from Carers themselves
 - Focus on frontline staff and those having direct contact with Carers, but also targeting Board members and Executives in order to get senior and political buy-in.
 - Share best practice from within the ABMU area and elsewhere ensuring a consistent approach to Carers
 - Accessibility of training is important – recognising staff workload pressures, take the training to staff not taking staff to the training, e.g. online tools
 - Use current training packages, rather than developing new e.g. RCGP Carers Toolkit for GPs.
 - Shift the focus from Patient to Patient and Carer.

- Ensuring staff are equipped to communicate the caring needs that patients will have as a result of their condition/illness and making sure Carers understand this
- Review of current support available for Carers during a patient's transition through services, e.g. links with Education when working with Young Carers
- Explore the range of services that Carers need and identify ways to capture these in information provision, awareness campaigns and advocacy services, e.g. availability of respite services for Carers. The aim of which will be to ensure quality and consistent services are provided in each area, regardless of postcode.
- Review the issues relating to information on identified Carers being shared between agencies. Once identified through a Carers Assessment, the documentation needs to be 'live' and regularly updated rather than used as a 'one off'.
- Identify information provided as a result of Carers Assessments and explore ways of using this data to plan services.
- Review all information available to Carers, locally and nationally and ensure access to this information is in a single point, the information is current and staff are aware of how to signpost Carers. This needs to recognise that there is not necessarily an issue with the quality of the information available, it is the mechanism for delivering the information that needs to improve. It is important to link the provision of information to existing mechanisms such as NHS Direct and future mechanisms such as the ABMU Communications Hub – also recognising that paper information remains important and points of access need to be tangible.
- Partnership working at all levels is important when delivering the strategy, such as maintaining current working relationships between Health Boards and Local Authorities and building on the engagement with Carers themselves, GPs, the Third Sector, etc. Organisations involved will also need to ensure internal partnership working is maintained, e.g. relationships with Mental Health, Education, Learning Disabilities, etc.

Appendix 4

Measuring up to the Measure Event – Bridgend

This conference was held on 20th July 2012 in order to raise awareness regarding the Carers Strategy (Wales) Measure 2010 and gain the views of staff and Carers concerning information and Carers services in the Bridgend area. The outcomes from the information mapping exercise, mentioned above, formed the basis of the workshops in the afternoon. Carers were invited to attend one of the workshops and give feedback. A full summary of the key themes emerging from the event can be found below:

1. Support to Carers

- Carers need good quality information that is widely available e.g. GP surgeries, hospitals.
- Carers should not have to chase information and it should be available at a much earlier stage.
- Carers need to be referred or signposted to the Carers Centre, Third Sector or Social Services at a much earlier stage.
- GP's need to be able to recognise Carers' stress and have awareness training – re what services are available to Carers
- GP's should have a register of Carers and have a system of prioritise GP visits when necessary. It is often difficult for them to visit surgeries.
- Carers need information and good quality advice regarding benefits e.g. forms and guidance notes written in an accessible form.
- Claim procedures need to be less bureaucratic. Carers often require help to complete forms.
- Social workers and other professionals need to be better informed to advise Carers to maximise their benefits.
- Carer's allowances are inadequate for a working 24 hour day.
- There is not enough respite for Carers or emergency respite.

- The closure of Maesgwyn respite has had a detrimental affect on Carers.
- Planning ahead for respite is difficult and individuals often have to have respite in a number of different care homes.
- The cost of specialist ambulance transport to respite is an area of great concern.
- There appears to be a general lack of resources allocated to Carers.
- Carers feel they are required to be assertive to get the help they deserve.
- If the “cared for” person refuses respite, the Carer is unable to have a break.
- Carers need financial information to plan for the future regarding Wills, Trusts and Power of Attorney etc,

2. Taking Control – Direct Payments and Citizen Directed Support

This workshop was principally to explain the Direct Payment process and what Citizen Directed Support and to respond to any queries.

- Further training is needed for staff to promote the use of Direct Payments and Citizen Directed Support and managed accounts.
- Carers need help to manage a Direct Payment and managed accounts.
- It is important that the contract of employment is detailed and clear to all parties.
- A number of issues regarding Personal Assistants were raised – Carers are concerned of upsetting Personal Assistants.
- Who is responsible for training Personal Assistants
- How are holiday and sickness periods covered?
- Confusion regarding what a Direct Payment can be used for.

- Personal Assistants can support social inclusion and provide tailored support
- Information regarding Direct Payments is disparate and depends on the social worker's knowledge.
- Concern that relatives who live in the same house cannot become Personal Assistants.
- What is the mechanism for dispute resolution?

3. Carers and Mental Health Measure

- Ensure good practice is promoted.
- There needs to be more involvement with Carers and service users in the planning and development of mental health services.
- A Carer should be involved and listened to when their family member is being assessed as often their input can provide a clear picture of any problems and contribute to correct diagnosis.
- Many service users do not want to go into a MH service.
- There is a perception of scarce resources for those who suffer with mental health problems.
- Families at times receive more assistance and information from 3rd sector than social services.
- The assessment process is long and arduous, it needs to be simplified.
- A carer related an experience that it has taken 38 years to get their son diagnosed. Other Carers agreed that it often takes a crisis to get help. Earlier involvement is paramount.
- Carers need information and training to help them manage their loved ones mental illness.
- A carer involved with an elderly mother could not get access to her medical information, which caused huge stress to the family.
- More information is required for the public as mental illness is "taboo".
- More information and services should be resolved to target staying well and preventive services.

- Carers fell strongly regarding the sharing of information for the “cared for”, especially where the cared fro is an adult.
- Carers should be able to re-refer for an assessment.

4. What can your GP do for You?

- Early identification for Carers in a proactive approach. Information services available in surgeries.
- Information sharing regarding issues of confidentiality, risk assessment and capacity.
- Improved links with Third Sector and signposting to resources.
- Better access to GP care and improved continuity.
- Better transition of care from Childrens Services to Adult Services.
- Improved access to end of life care.
- Proactive management of Carer’s health – regular health checks.
- Identification within each practice of a Carers Champion regarding Carer’s issues.

5. Have Your Say – Young Carers Workshops

- Need for more information on Young Carer’s issues e.g. posts which focus on Young Carers.
- Use of media, TV, digital story telling, publication of Carer’s stories.
- PSE days in school included in the curriculum.
- Young Carers are not noticed it is the disabled person/parent/sibling where attention is focussed.
- A Young Adult Carers group for transition – more Young Carers to be a Young Carers Champion.
- Young Carers do not want people to feel sorry for them.

- Need to change the perception in schools.
- Need to educate pupils at a young age what a Young Carer is to reduce stigma/isolation.
- Tasks/workshops in schools to explain the Young Carer's experiences.
- Carers Champions within schools.
- A Young Carer's project within the school led by young Carers (with permission).
- Young Carers are "hidden"; they are not given much help.
- Teachers are not informed regarding Young Carers issues; they don't know how to react/ what to do.
- Young Carers are missing out on school opportunities – they need more respite.
- There is added pressure on Carers
- There is no funding to support Young Carers.
- Wider society needs to be better educated.
- A mechanism for Young Carers to be identified but in a positive way.
- Help at home to support Young Carers with domestic tasks.
- More groups such as those facilitated by Action For Children.

Appendix 5

Training and Awareness Event – Neath Port Talbot

This event was held on the 27th September 2012 with the aim of raising awareness among staff of the Health Board and the Local Authority of their responsibility to meet the needs of Carers. Information was provided to Staff about the Carers Measure and discussions took place to identify gaps and training needs which could benefit them. Discussions also took place around future opportunities and potential ways that organisations and Carers throughout Neath Port Talbot could work together. The event was also used to inform Carers about what is available to support them in their caring roles and the support available in the area. An event evaluation was conducted following the day's activities and the results are included below:

Post – Event Questionnaire

Please complete and return the following questionnaire.

(Please ✓ as appropriate):

I am a Carer 22

I work for the Health service or Local Authority 18

Other, please state...13.....

Please circle 1 to 5

<p>STAFF - I am confident that if I have information about a person's circumstances, I can recognise if they are a Carer</p>	<p>Confident 😊 1...2...3...4...5 ☹️ Not Confident</p> <p>24 6 0 0 3</p>
<p>CARERS - As a Carer I am confident that the paid staff I have contact with would recognise my caring responsibilities</p>	<p>Confident 😊 1...2...3...4...5 ☹️ Not Confident</p> <p>7 8 2 1 5</p>
<p>I am confident that I know in general what the Carer (Wales) Measure is trying to achieve</p>	<p>Confident 😊 1...2...3...4...5 ☹️ Not Confident</p> <p>18 14 3 3 5</p>
<p>I am confident that I know what a Carers Assessment is and who can carry out an assessment</p>	<p>Confident 😊 1...2...3...4...5 ☹️ Not Confident</p> <p>20 13 4 4 3</p>
<p>I am confident that I know how Carers can access information and get support to maintain their health and wellbeing</p>	<p>Confident 😊 1...2...3...4...5 ☹️ Not Confident</p> <p>21 10 4 1 4</p>
<p>I am confident that I know about Community Transport and other transport services which Carers can access in Neath Port Talbot</p>	<p>Confident 😊 1...2...3...4...5 ☹️ Not Confident</p> <p>27 5 4 3 4</p>

<p>I am confident that I know about Neath Port Talbot Carers Service and the Services they provide</p>	<p>Confident 😊 1...2...3...4...5 ☹️ Not Confident</p> <p>30 7 2 1 4</p>
<p>I am confident that I know where Carers can get information about Housing and Benefits</p>	<p>Confident 😊 1...2...3...4...5 ☹️ Not Confident</p> <p>28 6 4 1 4</p>

<p>Overall I found this event....</p>	<p>Very useful 😊 1...2...3...4...5 ☹️ not at all useful</p> <p>18 11 3 0 3</p>
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- Is there anything that we have not covered in this session that you feel would have been helpful?
- Covered Very Well
 - What to do if Social Services will not help
 - Be able to get more help

- Most things covered
- More in depth discussion on the Carers Measure and how it will improve the Third and Statutory Sectors
 - Information and similar support and agencies available for young Carers
 - Young Carers
- Potential solutions for Carers from organisations that provide such eg. Replacement care/respice services
 - Young Carers issues were under represented
 - Carers Employment Rights
 - No, all the information provided has been useful
- Discussing the impact that becoming a carer has on any children in the family – the young Carers
 - An overview of the Carers Measure; Measure referred to but not discussed
 - More information about services for Carers caring for children

Do you have any other comment you would like to add?

- This is focused mostly on adults caring for adults
- Little bit confused as to whether the Carers Service refer to Social Services for Carers assessments or whether they will carry out themselves
- Include information about SNPY Crossroads Young Carers Project, The Carers Trust Schools Resource Pack and Caitlins Wish in Carers information for families so

So families know where to go to get support for children involved

- Excellent networking event, interesting talking to Carers about their roles and impact on their life, All I have spoken to has positive outlook and praised the help

and support from Carers groups and Carers service.

- We should consider making this an annual event
 - Good opportunity for networking as well
- As a professional I have found this really useful. Could this event be on an annual basis
- Well done to all in the smooth running of the event. To see how many Carers Were present shows the need to provide information and support
- Pleasant venue – site of all workshops too cold, workshops with facilitators rotating worked really well, workshops very informative and thought provoking
 - Having facilitators moving between workshops worked really well
- At times I thought some of what was said was negative and almost negated the Good work that is being provided by some of the services that presented today
- There is not anything for young Carers/not much said about young Carers regarding benefits and well being classes not much mentioned about the cared for person
 - Workshops well organised but also highlighted amount of facilities, Organisations and benefits who do not offer support to Carers under 18, i.e.

benefits, replacement care, well-being classes, discharge packs for Carers from hospitals etc.

- I found it difficult to hear individual speakers during group sessions due to background noise from the very
 - Very informative day
 - Learned a great deal
 - Just to say wonderful work
 - Thank god for the Carers Service
 - Continue doing good work
 - Very good day
 - Could not hear speakers/DVD
 - Your information was very helpful

Appendix 6

Swansea Carers Forum – Carers Measure Session

The Swansea Carers Forum is an established group of Carers and Carer representatives that plays an active role in the development of services for Carers in Swansea. This session took place on 5th October 2012 and was conducted as part of the Forum's regular meeting programme. Presentations were provided on the Carers Measure and then the group was asked to take part in an open workshop session to specifically discuss their needs when it comes to Information and Consultation. The session was lively and interactive and Carers were given the opportunity not only to comment on information and consultation needs but also raise issues and ask questions with regards the Carers Measure. The summary of comments and outcomes of the open session can be found below:

Information and Consultation

- Training & awareness of Carers needs to include Pharmacy staff, GP receptionists, dentists
- Identifying Carers – are the right staff being targeted?
- Accessing LA info ie. Housing dept
- Difficulties in sharing information need to be resolved
- Central co-ordination
- Need to raise profile
- More hard copy information as lack of access to IT by many Carers
- Carers assessments – printed assessment form sent to Carers prior to assessment meeting
- More eco mapping and identifying points of contact for Carers
- Carers Centre seems the only place for reliable information
- I didn't know what a social worker did or how to access them – we need to believe that you will do what you say

- People visiting GP surgeries should be asked 'are you caring for someone?'
- I need an operation but who'll look after my mum while I'm in hospital/ recovering?
- Carer social groups provide me with information – knew nothing before about accessing information
- More info regarding community cars
- Could do with more information on older people needing to move into care homes from hospital after illness
- More detailed information on actual process of contacting nursing homes info etc
- BME Support Group would welcome a visit to talk about the strategy

Miscellaneous

- Many Third Sector organisations now actively support statutory sector strategic objectives – there should be 2 strands of Third Sector agreements to acknowledge this – one for added value and support and one for meeting in – house targets, funded from central reserves
- Age is a barrier in health services
- As a working carer we should be able to earn a more realistic wage before losing Carers Allowance. Also why does CA stop when we become pensioners. Does the care stop too?
- Are there too many chiefs?
- Carer profile – Carers feel they are not valued so will not come forward
- Community development around caring/carers
- I don't fit into some services criteria and they are not flexible. More flexibility not tick boxes
- Departments not talking (housing, health, social services – makes it difficult for Carers creating delays, long delays for services/action
- Some services fit mum and my needs but not together
- Confusing criteria or criteria too high

Appendix 7

Carers 'Have Your Say' Sessions

A series of Carer Have Your Say sessions were conducted across Bridgend, Neath Port Talbot and Swansea in early Autumn 2012. The sessions were designed to allow Carers to comment and discuss the draft Information and Consultation strategy in an intimate setting at the Carers Centres in Bridgend and Swansea and also at the Neath Port Talbot Carers service meeting venue in Aberavon. The input from Carers at these sessions was extremely valuable and highlighted actions that have been captured within the action plan detailed later in this document. A summary of the outcomes from the Have your say sessions can be found below.

It is important to mention that at each of the above sessions Carers were not concerned with regards the content of the strategy, they just wanted to be listened to in their own time and as part of the group they felt comfortable with, rather than large open events. At times, the groups did not discuss the strategy at all but instead talked about the things that concerned them the most and the help they needed in times of crisis.

COMMENTS RECEIVED AT THE
NEATH PORT TALBOT CARERS "HAVE YOUR SAY" SESSION
WEDNESDAY, 3RD OCTOBER, 2012
ABERAVON BEACH HOTEL

Those present were asked to provide their comments on the following questions:

- Is the purpose of the strategy clear?
- Things you would like to see but are not in the document – What's missing?

- Is there anything you would like to add to the action points?

Comments:

- Strategy too complicated and contains too much jargon and technical data – Carers want to see a simple strategy that highlights way forward
- When the strategy is finalised an Easy Read version should be produced.
- Staff training is important
- Were Carers involved in the production of the e-training package?
- What about Carers who are staff, are they included in the strategy?
- Why is the action point relating to Staff Carers not being addressed until the second year? Needs to be addressed now. Action points need to be amended.
- Concern expressed as to the length of time it will take to implement the strategy. How long will it take to set up and how long will access to Carer assessments take?
- Definitely an easier format would be beneficial
- Development of an information pack. Carers would prefer that a person was on site to explain what was available. No time to read information pack.
- Carers need to be informed of where they can go to get assistance – Carers Centre, Carers Service, General Practitioners, Hospitals, etc.
- Strategy could be split into specific sections, i.e. Children, Elderly, etc. which would make it easier for Carers to read. They could go straight to the section that is relevant to them.
- Volunteers could provide explanation of what was available at various sites.

- Health Care Staff need to be aware of responsibility of Carers on patient's discharge from hospital as care responsibility could have changed.
- Easy Read leaflet could be provided at this point – combined approach required.
- Important to note that not all Carers are the same – cared for have gradual illness and some immediate. Important that appropriate information is provided.
- Training on what information is required when is essential.
- Easy Read Booklet with contact information and details of how services can help.
- Important that Local Authority take on board the comments as well.
- Carers lives complicated enough do not need any more confusion.
- Problem with information changing and needing to be updated on leaflets.
- Is it the Carer's Champion's responsibility to ensure that information is up to date? Important that telephone numbers don't change. Champions need to have experience of being a Carer.
- Easiest option is to have contact with an experienced person who is able to provide information rather than issuing leaflets/booklets.
- Staff training is a bigger issue.
- Money used for leaflets could be put to better use in the longer term.
- Last week's Carers Centre Training Session highlighted the need for one contact number along-side staff training.
- The development of a 0800 number for each of the Carer's Centre would be benefit as this would not change.
- Are you still a Carer when the "cared for" is living independently.
- Information should be available in different languages. What if they ring in – links to Language Line.

Post it note comments

- No Carer Allowance after 65.
- Getting one telephone number is important.

Group Session – Priorities

- Confidentiality – if using volunteers to provide information service would they be governed by the same Confidentiality Clause that Health and Local Authority Staff?
- Production of a Carer Counselling Helpline (same as Childline) where support and information could be provided 24/7.
- Important that Health Board revisit Carers Event to update on strategy.
- Information on the drop in service available at GP Practices/Hospitals needs to be publicised more effectively.
- Hold Carers Surgery Sessions same as those held by AMs/MPs in Community settings.
- Carers Diary – A useful tool which could include telephone numbers, details on services, important dates i.e. Coffee Morning's, Drop in Sessions, etc. This was seen as a better idea than the leaflet.
- Dates of Carers drop-in session to be publicised at the back of prescriptions.
- Use of different language required if Carers are to be targeted as many people do not see themselves as Carers. "Are you looking after someone – if yes, then you are a Carer".
- Use support groups to target Carers.
- Target specific internet sites, i.e. disability, NHS Direct, etc to provide link into Carers Strategy.

- Every form of communication needs to be covered!
- Carers need empathy and help not sympathy.

BRIDGEND CARERS "HAVE YOUR SAY" SESSION
WEDNESDAY, 3RD OCTOBER, 2012
BRIDGEND CARERS CENTRE

Those present were asked to provide their comments on the following questions:

- Is the purpose of the strategy clear?
- Things you would like to see but are not in the document – What's missing?
- Is there anything you would like to add to the action points?

Comments and questions received:

- What does the legal duty actually mean in the Measure – has it got teeth? Does it mean that the Health Board and Council can be prosecuted if they don't produce the strategy?
- Patients are not getting the correct treatment they need and this is a constant battle for Carers
- 1 in 7 Carers are staff working in organisations like the health board – you must do more for identifying Carers in the workplace
- Carers need to be involved in staff training to explain how they felt when things went wrong

- Young Carers need particular attention, not just leaflets and easy read materials, they need to be made comfortable to talk and express their views
- We need one contact point for information and advice – not just the Carers Centre
- Transport is an issue for Elderly and Young Carers – how are they supposed to get to a health appointment or meeting with social service if they can't access transport. This is especially important when considering visiting times at hospitals
- Confidentiality is a huge issue for Mental health Carers – need clear guidelines
- Psychiatrists must be given carer aware training package
- The strategy content is fine, it's the action plan that needs to be more prominent – Carers want to see action
- I feel more should be done to highlight the action plan not the words in the strategy – carer already know that but they want to see what you're going to do
- Benefits advice is a real issue for Carers
- GPs need to check for Carers
- GPs need to do far more to identify Carers and offer them support
- Communication important between Schools, GPs and Local Authorities
- Strategy needs to be clearer regarding what action you'll take for young Carers
- Welfare reforms are a huge challenge – not getting the help we need
- Lack of advice on benefits changes generally – the Local Authority need to do more in Bridgend
- Information is lacking on benefits advice, Carers counselling and access to respite services – the strategy needs to set out how the Council will tackle access to benefits advice
- Access to social workers is a nightmare - the waiting time is horrendous

- Social workers should be helping before the crisis happens
- Prevention services needed – not wait until the crisis
- If the Carer identifies themselves as a carer then we should all treat them as a carer – big issue with Local Authority eligibility criteria for this

Top Priorities:

- Need single point of access for information
- Need better information on benefits advice and welfare reforms
- Don't expect the strategy to solve the problems – just give us better information!

SWANSEA CARERS "HAVE YOUR SAY" SESSION
TUESDAY, 9TH OCTOBER, 2012
SWANSEA CARERS CENTRE

Those present were asked to provide their comments on the following questions:

- Is the purpose of the strategy clear?
- Things you would like to see but are not in the document – What's missing?
- Is there anything you would like to add to the action points?

Comments and questions:

- The strategy is clear and concise
- The document needs to be as simple as possible so that Carers can pick it up and understand what's going to be done – the action plan is good
- Need a section in the action plan for Mental Health crisis care
- It's not always obvious that the patient has a mental health issue – taking note of the family's views and observations is so important
- GPs need to help more
- I felt my GP didn't understand my situation and wasn't aware of the role of Carer
- One thing that has improved things for severe cases is the Medication Order at Cefn Coed Hospital, where patients are given their correct dosage of drugs even though they refuse. This is important for those that continually refuse to take medication
- Confidentiality issue – staff need to be absolutely clear about what info they can share and not hide behind this issue
- There is a 2 year wait for Psychotherapy
- Mental health Carers put a complete façade over things and their problems
- Benefits advice is not happening well enough – one advisor told my son that he doesn't cut himself enough to warrant certain payments
- We need more help with benefits and the changes coming in
- The changes to benefits are making things extremely difficult for Carers – constantly filling in forms and battling to get the right advice – the Council needs to do more
- It is so important that CPNs come out to the home before crisis point. Carers need advice on coping with their loved one before the crisis happens

- Carers need to be part of the training delivered to staff
- Crisis point is an absolute nightmare for Carers – the police don't respond quick enough and they don't seem to work in partnership with health and social care
- Some staff in Cefn Coed just assume that the patient can come home following crisis and treatment – sometimes they can't come home due to other issues within the home.
- Terminology and drug names are confusing – I carry a list around in my wallet, just in case the Psychiatrist prescribes a drug that has disagreed with my wife in the past
- Crisis is what ruins the lives of Carers
- We need advanced care planning in order to stop the crisis happening in the first place – this care plan needs to be prioritised
- GPs could help with care planning before crisis
- A plan that helps me cope with my loved one before the crisis happens would help