WLGA AND ADSS CYMRU EVIDENCE TO THE HEALTH, SOCIAL CARE & SPORT COMMITTEE'S INQUIRY INTO THE IMPACT OF THE SOCIAL SERVICES AND WELLBEING (WALES) ACT 2014 IN RELATION TO CARERS



# **SEPTEMBER 2018**



#### **About Us**

- 1. The Welsh Local Government Association (WLGA) represents the 22 local authorities in Wales, and the three national park authorities and the three fire and rescue authorities are associate members.
- 2. The WLGA is a politically led cross-party organisation, with the leaders from all local authorities determining policy through the Executive Board and the wider WLGA Council. The WLGA also appoints senior members as Spokespersons and Deputy Spokespersons to provide a national lead on policy matters on behalf of local government.
- 3. The WLGA works closely with and is often advised by professional advisors and professional associations from local government, however, the WLGA is the representative body for local government and provides the collective, political voice of local government in Wales.
- 4. As the national leadership organisation for social services in Wales, the role of the Association of Directors of Social Services (ADSS Cymru) is to represent the collective, authoritative voice of Directors of Social Services, Heads of Adult Services, Children's Services and Business Services, together with professionals who support vulnerable children and adults, their families and communities, on a range of national and regional issues of social care policy, practice and resourcing.

# The important role of carers

5. According to Carers Wales, there are 370,000 people caring, unpaid, for a family member or friend, and 3 in 5 of us will be carers in our lifetime. This is the highest proportionate figure of all UK countries, with 103,594 people in Wales providing over 50 hours of unpaid care per week. It is estimated that the care provided by unpaid carers in Wales is worth an estimated £8.1 billion a year. The number of carers continues to rise and it is estimated that by 2037 there will be over half a million carers in Wales - a 40% rise. Many do not define themselves as 'carers', but a family

member, friend or neighbour – however the act of caring, the time it involves, the physical and emotional expenditure, the impact on working life and social networks can significantly affect the carer's health and wellbeing, financial security and ability to meet their own life-time's goals.

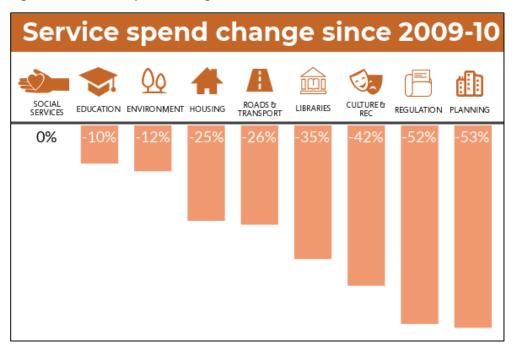
- 6. The demographic changes being seen across the UK will also have an impact on unpaid carers. An ageing population with improved life expectancy for people with long term conditions or complex disabilities means the need for more high level care provided for longer. We are likely to see more older people in a caring role, with the number of carers over 85 predicted to double in the next 20 years. Increasing hours of care often results in the general health of carers deteriorating incrementally. Unpaid carers who provide high levels of care for sick, or disabled relatives and friends, are more than twice as likely to suffer from poor health compared to people without caring responsibilities. Caring responsibilities can have an adverse impact on the physical and mental health, education and employment potential of those who care, which can result in significantly poorer health and quality of life outcomes. These in turn can affect a carer's effectiveness and lead to the admission of the cared for person to hospital or residential care, placing further pressure on our already over-stretched system.
- 7. Supporting and improving the wellbeing and rights of unpaid carers is important for councils who fully recognise the vital role and the significant contribution carers make to people with social care needs, and the wider health and care economy. Without these vital informal carers, the safety net of care and support they provide to thousands of people every day would collapse.
- 8. As a society, we need to do more to ensure the role of a carer is seen as a positive, rather than a stigma, and we are keen to work with Welsh Government, carers and carers organisations to make sure that carers are fully supported and signposted to services to avoid them and families reaching crisis point and care breakdown. It is fundamentally important for society as a whole that carers have the support they need to maintain their own wellbeing and to be able to lead fulfilling lives; to maintain social relationships; undertake education and training; maintain employment; and be active community members.

# Local government funding

- 9. Councils' ability to provide this well-being support is however undermined by the continued cuts to council budgets. If we are to achieve our aspirations for all carers who are needed in increasing numbers to address the rise in those needing care and fulfil the ambition and intent of the Social Services and Wellbeing (Wales) Act, Welsh Government needs to ensure that local authorities are adequately funded to meet the requirements that are being placed upon them.
- 10. Local government provides more than 700 local services, a significant proportion of which help improve wellbeing and tackle the social determinants of health. This includes housing, employment, welfare, leisure and transport and these help support the health and wellbeing of carers.

11. However, over the last 8 years Council's core grant funding has reduced by 22% after adjusting for inflation. If you take schools funding out, core funding has fallen by 35%. Figure 1 below shows how this reduction in funding has impacted on individual local government service areas.

Figure 1 – Service Spend Change



- 12. The statutory services of social services and education have been protected as far as possible by local government. This has meant that other non-statutory preventative community based services, such as leisure, parks, adult education, housing, transport and community facilities, all of which support carer's wellbeing and health, have faced the brunt of cuts to local authority budgets out of necessity. The report by Wales Public Services 2025, 'Austerity and Local Government in Wales: an analysis of income and spending priorities, 2009-10 to 2016-17', highlighted the significant impact that eight years of austerity have had on local public services. Cuts in the smaller but vital services have been deep, with question marks over their future sustainability if a further period of cuts were to continue.
- 13. Local government has kept the worst consequences of austerity at bay in recent years but its impact is now catching up with councils, threatening services that improve our lives and our communities, including services vital to supporting carers. We know that the cumulative financial pressures will continue to mount for local government over the next four years. Just to stand still on providing current services, local government would need a revenue increase of £264m (5% of net spend) in 2019-20 and 4% the year after. During this period unavoidable workforce costs will increasingly drive inflationary pressures and in 2021-22 and the year after, the overall inflationary pressures will run at around 3% in each year. Despite the best efforts of local government against the scale of the reduction outlined, these efforts can only go so far. Without a more fundamental review of how we fund services there is little wriggle room for further cuts. The current model is not sustainable, annual incremental budgeting just stores up problems for the future.

- 14. Further information on the financial pressures facing local authorities in Wales can be found in the WLGA's publication 'Fair and Sustainable Funding for Essential Local Services' <sup>1</sup>
- 15. In our evidence to the Health, Social Care and Sport Committee's scrutiny of the Welsh Government's draft budget we were clear that the local government funding position has serious consequences for wellbeing. It constrains social care which, in turn, constrains the voluntary sector and care providers. This all points to the need to urgently reform our current arrangements and take on the complex task of developing a long term sustainable funding framework for social care.
- 16. It is therefore welcomed that the new long-term plan for health and social care, *A Healthier Wales*, identifies the need to achieve a sustainable funding model for health and social care, recognising that health and social care currently consume a growing proportion of the Welsh Government's budget, at the expense of other public service areas, which also have a great influence on the health and wellbeing of the people of Wales. There is a desperate need for this work to lead to the provision of an additional source of funding for local government as part of an overall settlement that provides sustainable funding for all the vital services that councils deliver. All funding options to tackle the social care crisis must be on the table given the scale of the current crisis.
- 17. The recent announcement of additional consequential funding coming into Wales as a result of the UK Government's decision to provide an extra £20bn a year by 2023 to the NHS in England also provides Welsh Government with an opportunity to look at providing much needed additional funding to local government which would enable Welsh councils to plan with some surety over the next three years and provide local authorities flexibility to best meet local demand and needs, focussed on improving outcomes for their citizens and communities. Recent funding made available for social services from Welsh Government has only been for specific pieces of work and to support new initiatives rather than to be able to meet increasing demand and current pressures.

## **How councils support carers**

18. Both the WLGA and ADSS Cymru welcomed the principles of the Social Services and Wellbeing (Wales) Act, but we need to recognise the increasing expectations that are being placed on local authorities at a time of reducing resources. Working alongside Welsh Government, we have played (and continue to play) a key role in supporting the implementation of the legislation. The Social Services and Wellbeing (Wales) Act sets out important legislative changes for carers, crucially giving them the same recognition and parity of esteem with those they support. Local authorities have a duty to offer assessments and support plans for carers, developed with them as equal partners, and with the goal of enabling carers to live the life they want to achieve.

<sup>&</sup>lt;sup>1</sup> Available at: https://www.wlga.wales/SharedFiles/Download.aspx?pageid=62&mid=665&fileid=1754

- 19. These responsibilities that are specific to carers sit alongside other general provisions within the legislation, which are also relevant to carers. These include, for instance:
  - A duty to provide an information and advice service
  - A duty to ensure the provision of preventative services.
- 20. Under the Act all regions are also required to develop and publish Regional Population Needs Assessments, which provide an assessment of the care and support needs of their area, with carers being one of the core themes of the assessments. These assessments have now been completed and regions have also recently published their Population Area plans, another requirement of the Act. All identify the important and vital role that unpaid carers undertake and are committed to improving access to suitable breaks and respite that meet the varied, often complex needs of the people they care for. Regions recognise it is vital that all carers, young and old, need to have a break from their caring role, with a need for suitable and flexible respite opportunities to help support people to remain in their caring role. However, we also need to acknowledge the impact that funding cuts have placed on local authorities and their capacity to be able to continue to offer services such as these. Many regions are mapping or exploring more flexible options that meet specialist needs, such as autism or dementia. It is acknowledged that planning for carers services needs to consider the potential future needs of older carers and find ways of supporting older carers to plan ahead. Some regions have also highlighted concerns over the sustainability of carers services, which in many cases is provided through third sector support which is often reliant on short term grant funding.
- 21. The assessments identify that there are dedicated services for young carers linked to schools with additional one to one support and access to emotional support. There are examples of using social media to support young carers and involving young carers in service development. Respite and access to leisure opportunities are also available. A Team Around the Carer approach is also being utilised in one area. This supports the recent Care Inspectorate Wales (CIW) thematic review, 'In Support of Carers', which found that, "young carers generally are well supported", but warned that there are an increasing number with complex emotional needs and the lack of child mental health services means that workers supporting young carers are dealing with some challenging and complex issues.
- 22. A recent report by the Social Care Institute for Excellence (SCIE), 'Preventative support for adult carers in Wales' identified a number of examples in Wales of services that support carers, including:

## Services to support better identification and recognition of carers

Blaenau Gwent ran a Carers Engagement Project based within GP surgeries and run by the third sector on behalf of the local authority. The project employed carers support workers to raise awareness of carer support, to offer signposting and referral services, facilitate access to assessments and respite, and provide broader support and counselling

Rhondda Cynon Taf Council employs carers' champions, volunteer members of council staff who act as the main contacts for carer information in the service department in which they work. The network of champions encourage other staff to complete carer awareness training and gather carer information to cascade internally and to carers.

# Services providing information, advice and advocacy

The Welfare Benefits Service in Swansea is funded by Swansea Council to support carers, and prevent them from having to access higher tier and more expensive services. It offers benefits checks to maximise carer income, support with filling in forms and making claims, support with appeals and access to grants for carer support. Carers using the benefits service are also encouraged to make use of the full range of Swansea carers' centre services, which includes a local authority funded counselling service.

Dewis Cymru is a key information hub for carers looking for information or advice about their wellbeing. Funded and managed by Local Authorities across Wales so that information can be kept up to date and relevant. It acts as a signposting service for up to 6,000 local and national services across Wales.

#### **Shared Lives Wales**

There are 12 Shared Lives schemes in Wales, which is the first of the four UK nations to have Shared Lives services across almost every local authority area. Almost half (46 per cent) the people using Shared Lives in Wales in 2015 to 2016 enjoyed flexible, personalised short breaks and day support in a Shared Lives carers' home. Short breaks are an effective and affordable alternative to traditional respite care, particularly for families supporting people with dementia.

Caerphilly County Borough Council has addressed the emergency needs of carers through a range of measures, including advice on dealing with emergencies and an emergency card scheme together with a carers' time out service enabling carers to access time to attend their own appointments and health treatments.

- 23. SCIE has also published a series of practice examples which evidence the types of models of support available to carers in Wales (further details can be found in Appendix 1), with examples including:
  - Programmes of support being designed to support emotional wellbeing and improve outcomes in relation to isolation, stress and identity. This includes access to free training, workshops, social events and support networks.
  - Introduction of carers' emergency cards a credit card sized piece of plastic that denotes that the carrier is a carer and provides a number to contact in case of emergencies (24 hours per day). Ringing this number enables contingency support to be arranged.

- Carers Support Services which help carers in managing their health and wellbeing needs, providing support and advice
- Introduction of a dedicated carer's coordinator roles to oversee future developments and implementation of the Social Services and Well-being (Wales) Act 2014.
- Carers Champions whose role is to act as a liaison point between carers and services. They
  provide advice and information to carers; lead on carer issues at a service level and cascade
  information to their colleagues about what carers need.
- 24. Whilst much work is ongoing the SCIE report, 'Preventative support for adult carers in Wales' identifies that considerable challenges remain in providing consistent support and better outcomes for carers across the UK. They found that the most effective services in both England and Wales have been developed in response to local priorities, shaped by a strong carer voice at local level, and supported by proactive partnership working between health, social care and the voluntary sector. They aim to provide person-centred, holistic support tailored to specific needs. One of the key messages of the research is that caring is more than a health and social care issue, and to develop caring communities, carers' rights need to be embedded within broader health, social and employment policies.
- 25. One of the overarching challenges is identification, both encouraging people to self-identify as a carer but also with health and care professionals identifying carers, so that carers are able to access the information and support that is available. When carers do not conceptualise or identify themselves as carers but see the support they provide as a natural part of their relationship with the cared-for person they may be reluctant to come forward and fail to access benefits or support services, which could improve their quality of life. According to a poll published by Carers UK on Carers Rights Day, "the public is unable to recognise friends and family that care" with 51 per cent of those polled underestimating the number of carers in their own family, friendship network or workplace. Carers UK's 'Missing Out' report noted that in Wales 55 per cent of carers took more than a year to recognise their caring role, while 24 per cent took more than five years to identify as a carer. Early intervention, identifying carers before they reach crisis point, is crucial, as is identifying priorities and outcomes for carers on an individual basis once they have come forward to provide the right level and type of support. This has shown to be particularly true in relation to older carers (aged 80 years old or above) looking after a spouse or partner, BME carers, LGBT+ carers, and carers of people with dementia or mental health issues where there may be perceived to be an element of stigma and a wish to keep things private.
- 26. The challenge around identification and awareness is also evident from the recent figures which show that more than half of those offered a carers assessment refuse it, pointing to the need to increase our awareness raising efforts as part of an on-going process.
- 27. Issues of identification are compounded by those of accessibility. For example, carers living in remote or rural communities in Wales will have specific needs where social isolation, poverty, deprivation, lack of transport and long distances to travel to access health and care services mean

- that rural carers face additional challenges in accessing services. For example, if there are significant transport times this has an impact of the availability and length of time of respite care.
- 28. In Wales we need to have an overarching ambition to make being identified as a 'carer' a positive, with the support of our communities, so that more people can ask for support and not just monetary help to look after their own health, and ultimately benefit the whole of society, with a focus on encouraging people to self-identify as carers as a route to unlocking support from the community, public sector and businesses. This could include making it clearer that supporting the carer is supporting the one who is cared for, and that being a carer does not detract from being a husband, wife, sibling, daughter, son, friend, etc.
- 29. There is a need for practical recommendations on how to support carers who don't self-identify. The NHS and GPs are crucial in helping to identify carers, but there may also be more community-based or voluntary services adept at identifying and supporting carers. There may also be particular groups that are more difficult to identify. Working with other sectors, for instance faith groups, may open other avenues for engaging with these groups.
- 30. In our evidence to the Parliamentary Review we highlighted the importance of the workforce, and in particular the need to ensure that unpaid carers are recognised, valued and included as part of the workforce planning to ensure carers receive appropriate training and support for the roles they undertake. It is positive to see 'A Healthier Wales' identify the need to recognise and support the vital role played by the informal workforce of unpaid carers and the need for greater parity of esteem not just between health and care professionals, but with carers as well. The new long-term workforce strategy provides an opportunity to ensure that the workforce we have in Wales, including carers, feel valued and supported and are enabled to access relevant education, training and support opportunities.
- 31. There is also a need to recognise that the ability of councils to deliver any new ambitions is reliant on additional investment from Welsh Government. With a case for investment, whilst acknowledging that upfront investment to save money later requires that additional investment money to be available in the first place. There is a clear case here around the early intervention and prevention agendas for carers.

# Appendix 1 – Types of models of support available to carers

# Carers Resilience and Wellbeing Programme - Ceredigion County Council Carers Unit

Since autumn 2016, Ceredigion County Council Carers Unit have been working to deliver and evaluate a programme of support for local carers designed to support emotional wellbeing and improve outcomes in relation to isolation, stress and identity. The ultimate goal is to enable carers to become more resilient so that they are better able to cope with their caring responsibilities and prevent crises from occurring. The programme was originally designed as a means of supporting the wellbeing of frontline care staff and to reduce the risks associated with the high levels of stress and burnout that can be a feature in the sector. However, recognition of the role that family and friends play 'on the frontline' when caring for a loved one suggested that the programme might have wider applications. In response to a commission from the Mid Wales Collaborative and Hywel Dda University Health Board the programme was adapted for carers.

The programme encourages carers to develop a 'situational awareness' of their own resilience (and regularly consider at what level this is), and motivates them to improve this by taking part in activities that can improve their wellbeing. Underpinning this is a theoretical model drawing on a range of approaches from the fields of psychology, neuroscience and pedagogy.

The first phase of the project ran for seven months and was designed as a pilot service in order to determine whether the programme could be adapted for use with carers and to measure the impact of the programme on carers' outcomes (in particular those aligned with the Social Services and Well-being (Wales) Act 2014).

## **Carers Support Service - Vale of Glamorgan**

Carers support in the Vale of Glamorgan is being reviewed, with Cardiff Council, as part of their joint response to the Social Services and Well-being (Wales) Act 2014. This is part of the regional partnerships' work stream dedicated to carers. As the work stream is relatively new, the first objective is to conduct scoping work and map support for carers that is already in existence. This information is then fed in to a long-term strategy.

In terms of support for individual carers, a key piece of work has been the introduction of the carers' emergency card. This is a credit card sized piece of plastic that denotes that the carrier is a carer and provides a number to contact in case of emergencies (24 hours per day). Ringing this number enables contingency support to be arranged. The service is run jointly with Cardiff Council using existing record management systems and out of hours arrangements, and provides carers with reassurance that the person that they look after will be cared for if anything should happen to them.

The service also provides help with carers in managing their health and wellbeing needs. For those with relatively low level needs, the service enables them to experience a range of alternative therapies such as massages and holistic treatments. These provide an immediate relief from stress but during the course of the treatment, the carer is also given practical tools that they can take away that will help them to take care of themselves, e.g. in relation to their sleep patterns, diets, and nutrition. The key is to help them to recognise the importance of looking after themselves. Where a carers needs appear to be more acute the service encourages them to seek medical advice.

The council also commissions Care and Repair, a tailored service designed to help carers with small maintenance problems such as fixing a broken lock or a broken tap. Services are commissioned on a local basis, using outcomes based contracts. These are monitored using a Results Based Accountability system (on a quarterly basis). This has demonstrated good results in terms of the number of carers supported and the added value provided by the service, for example by identifying other issues and risks (e.g. fuel poverty) that can be addressed either directly support or by signposting to other services.

# Carers Project - Monmouthshire County Council and the Gwent Association of Voluntary Organisations (GAVO)

Monmouthshire Carers Project is an initiative run by Monmouthshire County Council and the Gwent Association of Voluntary Organisations (GAVO). The Monmouthshire Carers Project is the umbrella under which commissioned providers, the Monmouthshire Carers Strategy Group and carers work collaboratively in providing information, advice, events, training and support for each other, the third sector, social care, health and other organisations.

The programme provides free access and support for carers (via self-referral) including free training, social events, Carers Week events, Carers Rights Day (respite and transport can be provided so the carer can attend these events), the Carers Handbook, emergency and future planning booklet, carers emergency card and most importantly opportunities for carers to talk and be listened to. The goal is to be as responsive as possible and to ensure that services are designed with input from carers.

The initiative also places an emphasis on the role of GP surgeries in supporting carers with the Investment in Carers scheme (developed in collaboration with Hwyel Dda Health Board). The Investors in Carers scheme is a framework of good practice which GP practices can utilise to develop their carer awareness and ways of working to support carers on their patient register.

Another key strand to the project is the young carers strategy, which was developed in collaboration with a group of young carers and highlights the importance of working with providers to provide preventative support.

# **Carers Support Service - Caerphilly County Borough Council**

Caerphilly County Borough Council carers support service is an inclusive support network that seeks to improve carer outcomes and promote the caring agenda. The service has been a long standing service, however it was significantly development through the introduction of a dedicated carer's coordinator role to oversee future developments and implementation of the Social Services and Well-being (Wales) Act 2014. This post was established in September 2016 and has resulted in the service being able to provide a wide range of support. This includes the organisation of frequent social events as well as activities during Carers' Week and Carers' Rights Day. The service also provides information through newsletters and mailing lists (both in print and electronically) and staff manage an online carer support group (using a closed Facebook page). The service has also worked in partnership with neighbouring local authorities and health board to establish the carers grant scheme. They have relaunched the carer's emergency card and the 'time out' respite service.

Team members also work hard to promote the importance of carers' assessments and ensure that all carers receive an assessment if they wish to do so. However the service is an inclusive one and will ensure carers have access to all necessary information and support groups even if they do not wish to have a carers assessment. The first task for staff was to identify what was important to carers and what barriers there were to achieving this by asking 'what matters to you?' The intention in asking this question is to ensure that the focus is upon the carer as an individual and not purely on their role as a carer. The assessment remains focused on identifying potential solutions rather than simply listing problems (a cultural shift in assessment practice). This approach has seen many benefits to carers, including carers being supported to access small breaks, education opportunities, and support to carers to meet their own personal outcomes and continue in their caring role.

Since its inception, the carers coordinator role has ensured the objectives of the service have expanded to become more strategic in outlook are underpinned by a recognition that to be effective the service must be responsive to the needs of the local carer population. This was in part informed by consultation on a carers rights day held in November 2016, where the emphasis on outcome focused, person-centred support that recognised the needs of the individual was identified.

Consequently, there is a significant focus on engagement with local carers to provide a clearer understanding of their needs, and to determine which aspects of support are working well and which are not. By doing so it is hoped that a more sustainable and responsive service can be provided which will prevent crises and reduce the need for intensive intervention, thereby meeting the requirements of the Social Services and Well-being (Wales) Act 2014. Over the next two years a range of consultation events are planned to inform the development of the service strategy, including an event specifically for young carers.

The service is funded by the council, the integrated care fund and is staffed by a small team of four. A range of other organisations are also involved; for example the carers grant scheme is overseen by the Carers Trust and services for young carers are contracted to Barnardo's.

#### Carers Support Service - Rhondda Cynon Taf County Borough Council

Rhondda Cynon Taf (RCT) Borough Council's carers support project provides support and advice to individuals living in the area who care for a family member, friend or neighbour who is ill, frail, has a disability, suffering with a mental illness or substance misuse problem. The service has been running for twenty years and takes an early intervention and prevention approach to support aiming to meet low level needs of carers in order to prevent crises. The geographic profile of the area can make it difficult to co-ordinate support as the borough is relatively large and the towns often lie some distance from each other. As a result, the service has to be a little more creative in the way it works, with events being held in places such as local job and leisure centres.

The service is run by six members of staff working both full and part time. Referrals can be made from health and social care practitioners as well from the third sector professionals and from self-referrals. Support is provided through a range of projects. In addition to one to one assistance and signposting to carer's assessments and direct payments; the service also produces a carer's newsletter, an in house counselling and peer support service, advice regarding legal problems and facilitates access to local authority services. The service also regularly runs outreach services and coffee mornings as a means of informal support as well as working with the Past Carers group to support individuals whose caring roles have come to an end.

The Project has strong links with RCT leisure services and offer discounted access to carers to council run leisure facilities in RCT. A key piece of work that has proven very popular amongst local carers is the Carers Emergency card. This is a credit card sized card that carers carry with them and is used as source of identification in case they have an accident or are suddenly taken ill. By ringing the support line number on the card (staffed 24 hours per day and 365 days per year) help can be arranged for both the carer and the person whom they look after.

The Project provides a range of workshops, events and training to carers across RCT. These include anything from first aid, manual handling, stress busting and healthy eating, to family fun days, relaxed inclusive cinema screenings and the more social craft workshops and team building opportunities. All of this is provided to carers free of charge. The service also provides targeted support, with staff focusing on carer populations with more unique needs, for example, young adults (helping with work, education, etc.) and parent carers of children with additional needs (working closely with the Disabled Children Team). Staff also work with the Alzheimer's Society to run the Carers Information and Support Programme (CRISP) which provides support to carers of people with dementia and empowers them to address their own wellbeing needs.

In addition to working with individual carers, the service also aims to help services to understand the needs of carers through the Carers Champion role. The role of a champion is to act as a liaison point between carers and services (their employer). They provide advice and information to carers; lead on carer issues at a service level and cascade information to their colleagues about what carers need. There are currently champions working in a range of settings such as day centres, children's

services, colleges and schools, community teams, home care services, housing teams, job centres, leisure centres, social care teams, and welfare rights teams.