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Social Care **Wales**



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Preventative support for adult carers in Wales: rapid review



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A rapid review of preventative support for adult carers in Wales

“Our vision for carers in Wales is one where communities foster a carer-friendly approach, identifying and supporting carers so that they are not disadvantaged or discriminated against as a result of their caring role.”

**Huw Irranca-Davies, Minister for Children and Social Care,
Carers Rights Day, 24 November 2017**

Introduction

This overview of good and emerging practice in the development of preventative support for adult carers in Wales is one strand of a broader package of work by SCIE, commissioned by Social Care Wales in 2017. It is intended to support Social Care Wales in realising its ambition to improve well-being by promoting evidence-based policy, practice and service models that have a focus on prevention and early intervention.

In its strategic plan for 2017 to 2022, Social Care Wales acknowledges that more can be done to support unpaid carers and families. It is estimated

unpaid carers and families provide 96 per cent of the care in Wales, enabling vulnerable, sick and disabled people to maintain their independence and continue living at home (Social Care Wales, 2017).

The expectation is that this review will help inform the development of Social Care Wales’s service improvement planning over the next five years, and the organisation’s response to the recent announcement by the Welsh Government of new national priorities for carer support.

Methodology

Aims

- Drawing on key recent research and reports, this rapid review seeks to identify emerging good practice, new models or innovation in adult carers support, and particularly, support that reflects a preventative approach. It includes reference to selected examples of services and interventions from Wales and England that have been shown to address identified carer needs, and improve outcomes and carer satisfaction.
- The focus is on the range of support for adult carers – people aged 18 years old or above who care on an unpaid basis for disabled, frail or ill family members including children, friends or neighbours. Although many of the approaches are also relevant to, and benefit, young carers, specific interventions for young carers were agreed to be out of scope for this review.
- The Social Care Institute for Excellence (SCIE) is developing new carers pages on its Prevention and Well-being resource, reflecting the key themes in this review and featuring some more in-depth examples of carers services in Wales. These will be published in 2018 and linked to the Social Care Wales website for wider dissemination.

Literature review

This summary is based on the findings of a focused literature review (looking at a range of material published since 2011), some additional desk-based research and a small number of telephone interviews with representatives of carers organisations in Wales. The work to identify relevant service examples and create more detailed profiles for publication is ongoing and will be completed by March 2018.

Further details about the search methods, other sources and interviewees are given in Appendix B. It should be noted that this piece of work is not a systematic review, and that the findings and case studies are included as examples of current positive practice to stimulate discussion rather than to offer replicable models of carer support. Given differences in local populations, geography and models of delivery comparing service models with a view to replication or scaling up is of limited value. What comes through strongly from the research is how much local priorities have shaped effective service provision. However, sharing the knowledge and learning from this good practice is a valuable first step to help inform service improvement and the development of new ways of working with carers.

What do we mean by innovation in relation to provision of carers support?

- the delivery of traditional forms of support in new settings e.g. creative breaks provision
- provision and delivery of initiatives through new partnerships and joint working, including social enterprises, co-operatives and small community organisations
- using new ways to deliver existing services and making them more accessible, for example, through information or assistive technologies
- the creation of new whole system models.

Review findings

Research about carers

Current estimates by Carers UK predict the number of unpaid carers needed to support people living in their own homes in the UK will increase from 6.5 million to 9 million by 2017 (National Institute for Health and Care Excellence, 2017). In a climate of public sector cuts and continued demographic pressures, mapping what is known about what works in the provision of carer support, and developing new models that address carer needs and are effective is essential.

Carer-related evidence and knowledge is complex and fragmented, and much of it is grey literature-based. It comes from a wide variety of sources including academic institutions, peer-reviewed journals, national and local government bodies, policy and campaigning organisations, and grassroots bodies representing carer voices (Henwood, 2017). In recognition of the expanding academic field of carer research, a new multi-disciplinary journal, *The International Journal of Care and Caring*, was launched in 2017.

The rise of carers as a focus of research has paralleled the growing recognition of carer issues within public policy over the past two decades. But much of the published literature focuses on carer characteristics, the lived experience of carers, and the nature and duration of their caregiving. Although this is valuable evidence in raising the profile and diversity of carer needs, and of course in informing campaigns for policy change, less is known about the effectiveness of different interventions to support carers – and about which type of intervention works best for particular carer groups.

The impact of caring is also well-documented and represents a substantial and growing body of research. Although caring exists in multiple forms, and involves supporting people with distinctive and specific needs, there are many aspects of caring that are common to most carers and it is recognised that caring impacts on all aspects of a person's life, and not just in the ways that may be more immediately obvious. Research has shown that often it is the

process of accessing and receiving support (and thereby recognition) that is valued by carers as much as any particular outcomes that may have been identified (Henwood, 2017).

The detrimental impact of a lack of effective support on carer health and well-being is a key theme of Carers UK's latest annual State of Caring report (Carers UK, 2017). The report highlights that the new legal duties to support carers in both England and Wales have yet to become a practical reality on the ground.

The National Institute for Health and Care Excellence recognises that the quality and consistent provision of support available to unpaid carers varies widely across the UK and that to address this challenge, new guidance is needed to provide "action-oriented recommendations for good practice" (National Institute for Health and Care Excellence, 2017). Currently at the scoping stage, new guidelines will be produced in 2018 and will inform the publication of a Quality Standard for carer support.

Considerable challenges remain in providing consistent support and better outcomes for carers across the UK. 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.

There is a lack of high quality evaluations for the different types of intervention currently on offer and particularly in relation to the differential effects for these interventions on different groups of carers. There is no "one size fits all" model of carer support. What is important is that carers themselves are supported to play a key role in developing the services and support that best suits their needs.

Carers in Wales

Families, carers and their immediate communities provide the foundation of care and support for frail, sick, disabled and vulnerable people living at home, with unpaid carers saving the state the equivalent of £8.1 billion in Wales each year (Carers Wales, 2015). The Parliamentary Review of Health and Social Care in Wales acknowledges this vital economic contribution that Wales's 37,000 carers make to the Welsh health and care system (Welsh Government, 2017). Wales has the highest proportion – at 12 per cent – of carers in the UK (more than in any one region of England), and the highest proportion of older carers and of carers providing more than 50 hours' care a week.

In November 2015, Carers Wales held its first Carers Assembly, which highlighted issues raised by carer representatives before the enactment of the Social Services and Well-being (Wales) Act 2014. The Act is a substantial piece of primary legislation that makes significant changes to how social services in Wales operate (Welsh Government, 2015).

Before the introduction of the Social Services and Well-being (Wales) Act 2014, there was no statutory framework in place in Wales in relation to preventative social care support for adults. As with the Care Act 2014 in England, the Social Services and Well-being (Wales) Act 2014 is underpinned by a preventative, person-centred approach to improving well-being, promoting the prevention of escalating need, and making sure the right support is available at the right time for those who need it.

This principle applies to any vulnerable person who needs care and support, whether they are a direct user of services or supporting somebody else to live independently. New service models that have the citizen at their core, and that seek to protect and support all opportunities for independent living, are at the heart of health and social care transformation across Wales (Welsh Government, 2017).

The Act gives carers living in Wales the same legal rights and entitlements as those they care for. 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.

It reflects the principle that carers, if effectively supported, provide a preventative service in their own right, enabling people who are frail, vulnerable or have long-term conditions to stay living at home longer and as members of their local communities.

On Carers Rights Day (24 November) 2017, the Welsh Government reaffirmed its commitment to carers with the announcement of £1 million in 2018 to 2019 for local health boards to work collaboratively with partners to address three national priorities to improve support for carers by:

- identifying and recognising carers
- providing information, advice and assistance
- supporting a life alongside caring.

In support of this work, a Ministerial Advisory Group will be set up as a cross-government national forum to inform the provision of improved services for carers and develop proposals for nationally funded projects in 2018 to 2019.

Key challenges

Implementation of the Social Services and Well-being (Wales) Act 2014 by local authorities is still at an early stage as far as indications of significant change in carer experience on the ground are concerned. Carers Wales is monitoring local authority progress with implementation through their Track the Act survey and bulletins, which gather evidence from carers across Wales about the provision of information about carers' rights and access to assessments (Carers Wales, 2017).

In England, where legislative changes to carers' rights were introduced a year earlier, the Care Act for Carers One Year On Commission reported that despite some carers receiving good support and examples of positive practice, much remained to be done to ensure that carers are aware of their rights and that the quality of assessments offered are of a consistently high standard (Bennett, 2016). Feedback from the Track the Act bulletins indicates a similar situation in Wales.

There is a concern expressed by some organisations that support for carers is not at the forefront of planning and provision for local authorities, and has slipped down the agenda in the overall drive to transform social services. More support is needed for effective implementation, particularly in relation to cross-sector approaches. There are also concerns that the subsuming of the 2010 Carers Measures legislation into the Well-Being of Future Generations (Wales) Act 2015 has resulted in a loss of profile for the carers agenda in health and social care, and will impact on carer identification (Carers Officers Learning and Improvement Network, 2017).

Many of the examples of positive or innovative local practice for adult carers in Wales have been developed since the 2013 Carers Strategy (Wales Government, 2013) and are provided by third sector organisations. The role of third sector organisations in running local preventative services is explicitly recognised in the Social Service and Well-being (Wales) Act 2014 through a new local authority duty to promote the provision of user-led services and activities.

There are more than 33,000 third sector organisations active in Wales, more than 10 per cent of which work in health and social care (Welsh Institute for Health and Social Care, 2017). These encompass registered charities, social enterprises, co-operatives and community organisations.

The sector has traditionally played a critical role in supporting people with care needs in the form of specialist support groups, respite care, and social and community groups across Wales. It has also led on the

provision of innovative models such as Shared Lives and Community Circles. The creation of alliances, such as Age Alliance Wales and the Carers Alliance, have enabled the bringing together of organisations with shared or complementary goals to improve carer provision through collaboration.

The support carers say they need is varied and diverse and reflects the range and diversity of the caring role and the people who perform it. However, recurring themes raised by all carers relate to rights, assessment, adequate information provision, provision of suitable respite care and the negative impact of caring on work and finances (Carers Wales, 2015).

Evidence shows that investing in carers through better commissioning can reduce admissions to hospitals and residential care, and delayed transfers of care. It can also reduce carers' needs to access primary care, and improve both carers' health and the health of the people they care for (Carers Trust Wales, 2016).

However, funding for carers' support remains largely short term, which is not cost effective and contributes to ineffective commissioning. Sustainability of services, particularly in the third sector, presents a key challenge. The Wales Council for Voluntary Action has called for a new approach to funding and commissioning care to facilitate moving away from a reactive approach addressing immediate priorities to longer term funding and investment in the development of preventative services as embodied in the Social Services and Well-being (Wales) Act 2014.

Preventative support for carers

Preventative services for carers are provided by a range of providers but all aim to provide timely and targeted information and support to reduce or prevent the likelihood of carer crisis and breakdown, and improve the overall quality of carers' lives. If effective and operating as an integral part of the health, social care and well-being infrastructure, they should reduce demand for more costly health and care services.

Characteristics of effective preventative support services

- carers are supported in their own homes and as active participants in their wider communities
- services take a proactive approach to identifying carers (and potential carers) and target support appropriately
- use asset and strengths-based approaches to identify what matters to carers and are not focused on a deficit or needs-based model
- help build community capacity and develop carer-friendly communities
- are user-led and rooted in co-production and co-design
- the support provided addresses the whole person and aims to keep carers healthy as part of maintaining their overall well-being and improving their quality of life
- offer a tailored mix of universal services, for example, a universal information, advice and advocacy offer with appropriate referral pathways; secondary services, such as crisis management and emergency planning; and tertiary preventative support, such as respite, short break or "replacement" services
- provide practical support aligned with emotional support, such as counselling, peer support and psychosocial interventions
- support recognised transition or "pinch points" in the carer life cycle. For example, becoming a carer, when the cared-for person is admitted to a care home/hospital, when a cared-for child moves from children's to adults' services, at end of life, and when caring responsibilities cease
- are based on partnership working and effective collaboration between health, care and third sector organisations with clear communication, data sharing and referral processes
- providers are able to demonstrate the social and economic value of services provided through a mix of sound evaluation measures, accurate carer data and positive carer stories.

Key themes

Identification and recognition

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 press release for Carers Rights Day, 2017).

As the literature shows, caring is an extremely diverse experience and one that involves all populations, ages and social groups. Many people are likely to experience one or more periods of caregiving over a lifetime and some have multiple caring responsibilities. For example, “sandwich carers” who may be looking after different generations within the family and often also working.

Some carers are less visible than others and have been described as “hidden” or “hard to reach” and may have been overlooked in the mainstream care discourse. The needs of older LGBT+ people caring for partners and friends is an area that has only more recently featured in research and where more research is needed (Henwood, 2017).

Of the nearly 7 million carers in the UK, it is estimated that many are not likely to be receiving the support they are entitled to. The Social Service and Well-being (Wales) Act 2014 gives carers new rights in relation to assessment and having their needs met as a result of that assessment. However, one of the most common complaints from (identified) carers is that they have not been informed of their entitlement to an assessment or their right to seek a direct payment (Carers Wales, 2015).

Despite the rights enshrined in the new legislation, there is a perception that local authorities tend to be more process or system driven and that the required cultural changes will take much longer to embed. The Wales Carer Officers Learning and Improvement Network (COLIN) report that one reason for the success of third sector services in attracting more carers to come forward relates to a

perception that there is less stigma in approaching voluntary organisations than requesting a local authority assessment (Carers Officers Learning and Improvement Network, 2017).

It has also been suggested that despite the changing legislative context of a greater focus on carers’ rights, there may be some practitioner ambivalence towards carers’ assessments because of a perceived lack of new types of support for carers for referral following an assessment (Seddon & Robinson, 2015).

Identification is a key obstacle, both self-identification and identification by health and care professionals. 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. 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.

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 (Carers UK, 2016). 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.

Issues of identification are compounded by those of accessibility. Crossroads Care (Carers Trust) has highlighted the specific needs of carers living in remote or rural communities in Wales 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.

What are the desired outcomes for carers in relation to identification and recognition?

Carers:

- are appropriately identified, able to recognise that they are a carer, and able to express a choice about their caring role, and the type of support they need
- are listened to, treated with respect and feel valued
- know their rights and understand the support that is available to them
- have the opportunity to make their voices heard and are genuinely involved in all decisions that affect them and the person they care for
- are involved in the strategic planning, and provision and evaluation of the services and support they receive
- receive support that is appropriate and tailored to meet their specific needs (is culturally and socially appropriate and accessible).

Specific needs and issues have been identified for different carer populations including:

- carers of adult children with drug and alcohol dependency who often experience marginalisation and stigma attached to addiction (Adfam, 2017)
- parents of learning disabled children – increased life expectancy of people with learning disabilities means they are more likely to be living with an ageing family carer (Taggart et al, 2012)
- adult children of ageing parents (Bastawrous et al, 2015)
- sibling carers of people ageing without a spouse, partner or adult children (McGovern & Gardner, 2015)
- “sandwich” carers – usually women aged 50-65 who are juggling caring for elderly parents and grandchildren, as well as maintaining paid employment (Ben-Galim & Silim, 2013)
- older carers 85+ where caregiving is likely to be taking place in the context of a long-term relationship and where dementia is often a feature (Carers Trust, 2015a) – and older former carers experiencing bereavement (Larkin & Milne, 2017)
- older members of BME populations living in Wales (Blood, Copeman & Pannell, 2016)
- male carers (Slack & Fraser, 2014) and particularly

older men, a growing group of 70+ men looking after a spouse or partner

- LGBT+ carers (Carers Wales & Cymru Pride, 2017)
- carers of people with dementia particularly in relation to “relieving the burden of care” with support programmes focusing on risk management and managing challenging behaviours (Sutcliffe et al, 2016)
- carers of people with mental health needs (Hafal, 2016)
- carers living in rural or remote areas (Crossroads Association Wales, 2017) and particularly carers of people with dementia who are more likely to feel isolated and unsupported (Alzheimer’s Society, 2016).

Examples of services to support better identification and recognition of carers

A preventative focus on early identification with a view to minimising risk of carer hardship and crisis, the embedding of identification systems across integrated models of primary care, public health and the voluntary sector, and the utilisation of community-based initiatives such as asset-based community development (ABCD) and local area co-ordination (LAC). These include:

- carers’ prescription services and social prescribing models, working with primary care through GP registers and care champions
- outreach services, such as a mobile “carers’ surgery” services, home visits for carers, meetings organised in local centres and social spaces at times that can accommodate working carers
- carers’ “passports” or identity card schemes that support recognition and offer benefits, local discounts, priority appointments and emergency support
- making use of existing community assets and other professionals to support prevention initiatives – for example, mobile library or blood donor services, hairdressers, fire service, pharmacists, local businesses to help identify carers, supply basic information and signpost. This might include something simple, such as providing carers’ support information in local pharmacies and using stickers to highlight this on prescriptions.

In Salford, Carers UK has identified that 10 per cent of the population are carers and 43 per cent of these are providing care for more than 20 hours a week, many of them to people with long-term conditions, including mental health issues and dementia. One of the main aims of the Greater Manchester West Family and Carers Strategy is to support carers to remain mentally and physically well since full-time carers are twice as likely to be in poor health as non-carers.

The Salford branch of Crossroads Care provides a Carers Breaks Prescriptions Service, the provision of free tailored short breaks for carers (minimum four hours) referred through GPs' prescriptions once the carer has made an initial contact.

In Wales, 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.

A similar scheme offering an integrated approach to the identification of carers was run by Bristol and South Gloucestershire Carers Support Centre offering a Carers Health Project funded by the clinical commissioning group. The GP practice hosts a link volunteer based at the practice and trained by the carers' centre to identify carers and signpost them to appropriate support, referring them to the carers' centres if more in-depth support is needed. Carers' surgeries offering one-to-one advice are held on a monthly basis and carers are identified on patient recording systems. All practice staff including receptionists are trained in care awareness.

Herts Help service in Hertfordshire uses a place-based social prescribing approach based on expert triage using carer champions in primary care and community navigators.

Action for Carers Surrey has been commissioned to provide a county-wide carers' support service building on an existing GP Carer Awareness service and expanding to include a presence in the county's five acute hospitals. The new model offers flexible support, including a new range of digital resources to complement print-based materials.

York Carers Centre offers training to GPs to make them more carer aware, encouraging them to ask patients if they care for someone when they first register or during the course of an initial consultation. Staff nurses are trained as carer champions and the centre encourages the use of social media, as well as noticeboards to raise awareness of the support available.

Carers FIRST in Kent and Medway also offer practical support to GP practices to facilitate identification of carers alongside training in carers' needs and well-being issues. The "carers' surgeries" initiative was promoted by an awareness of a disparity in practice in relation to carer identification within one area in Kent and the need to generate greater carer awareness and a more joined-up approach.

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.

A carers' champion network was set up by Cwm Taf University Health Board to profile and support the role of carers across a range of service settings, health, social care, education, housing and leisure.

Information, advice and assistance

What are the desired outcomes for carers in relation to the provision of information, advice and assistance?

The consequences of not getting the right information at the right time can mean carers missing out on both practical support and entitlements to benefits – for example, obtaining Carers Allowance or knowing about the option to take up a Direct Payment. The lack of communication or poor information exchange between health and care professionals (GPs, district nurses, social workers) and different agencies also places additional burdens on carers when trying to access assistance.

Having to repeat their story many times to different agencies when seeking support is a common carer complaint as is the amount of time spent on what could be called “care management”, arranging appointments and keeping an audit trail of applications, paperwork and telephone calls made to different organisations.

Evidence shows that while a wide range of information is produced by health and social care organisations across the statutory and voluntary sectors, often the onus is on the carers themselves to seek this information out (by requesting a carers’ support pack, for example). Information is often not available at times of crisis or transition, for example, when the person cared for is discharged from hospital or enters a care home (Care and Social Services Inspectorate Wales, 2017). The need to have more information available at the point of becoming a carer has been highlighted (Carers Wales, 2015) as has the need for information in Welsh without having to make a special request for it and the need for Welsh-speaking support groups.

Carer outcomes in relation to information and advice

- a single “port of call” location – for example, a carers’ hub for information and/or named co-ordinator to act as a referral point and effectively signpost to other provision
- receipt of the right information at the right time

- and in appropriate multi-media formats (digital, print-based, in appropriate languages for the local community, face-to-face)
- expert support and advocacy is available to help carers with welfare rights claims, applying for assessments, legal issues
- information and advice is based on what matters to the carer – use of what matters conversations and strengths-based assessment by local authorities and other providers
- information available is both universal (i.e. what the basics are), a blend of national and local information, and targeted to the needs of specific carer groups
- carers are able to access specialist information – for example, on what to expect in relation to specific long-term conditions, managing medication and prescriptions, awareness of behavioural and physical changes particularly in relation to dementia and mental health conditions.

Examples of 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.

Carers Wales has published Being Heard – a self-advocacy guide for carers that offers an integrated group of resources to help carers navigate the system, communicate effectively, make effective complaints and advice about self-managing the range of emotions that can arise for carers around the caring role.

Powys carers’ service Credu has developed a programme of outreach work to make connections and build relationships with carers. Advocacy support is offered through appointments in carers’ own homes or in local cafés helping carers with completing forms and benefit claims. The service says that this form of support has more than a practical benefit to carers in

that the process of form filling also helps build trust and a deeper relationship.

In Worcestershire, a new integrated carers' hub supported by the local authority and clinical commissioning groups was launched in July 2017. The Hub supports carers across the county and aims to offer a "one stop shop" for carers providing Carers Pathway Advisors (telephone and drop-in advice); monthly carer support groups; carer training and a telephone befriending service (Listening Ear) aimed at people caring for someone close to the end of life. A companion service Carer Talktime offers telephone contact with trained volunteers to reduce social isolation and loneliness. Working with partner organisations using a community engagement model helps to raise awareness, reach greater numbers of carers and improve carer access to Hub services.

Local service provision should be aligned with resources provided by national information services, such as Dewis, the online well-being directory for Wales that supplies information about carers' rights, accessing practical support and learning skills to support carers.

Established advice and information services can be enhanced through digital platforms and use of social media to create comprehensive online services for carers linking national and local information providers and a range of cross-sector support. Anglesey's Linc Cymunedol Mun service offers a single point of access co-ordinating information on behalf of the local authority, health and voluntary sector.

Carers UK has produced the Upfront guide, an online service to help carers navigate the benefits system (backed up by their telephone advice service) and offer an online peer support forum where carers can exchange information and advice.

Most of the major carer organisations are also making greater use of social media, such as Facebook and Twitter, to promote their services.

Support for a life outside the caring role

Carers want flexible, integrated support from services that talk to each other and are co-ordinated. Services should be holistic in approach, recognising that caring may impact on all aspects of a carer's life.

What are the desired outcomes for carers in relation to support?

- carers are supported in maintaining their own health, well-being and quality of life
- they are supported to access or maintain employment, training, education, and leisure and social opportunities
- they receive timely and appropriate practical and emotional support, and are supported as early as possible, at points of transition and when the caring role ends
- carers are able to access support, which builds their resilience and coping strategies alongside practical support, such as breaks and social activities.

Respite, short breaks and replacement care

Being able to take a break from the demands of a caring role is essential for most carers and the availability of appropriate respite and replacement care is one of the most frequently raised carer issues (Carers Trust Wales, 2017). What connects all carer support measures is their ability to contribute to what is termed "carer resilience" to generate the desired outcome of sustaining long-term family care (Parkinson, Carr, Rushmer & Abley, 2016). Support for a life outside caring focuses on enabling carers to maintain their emotional and physical well-being recognising that the needs of carers can fluctuate and change over time, and that support may also be needed after the loss of the cared-for person when a long-term carer may struggle to adapt to life post-caring.

However, what makes the most difference may not be the standard service offer. An approach that views respite not as a discrete intervention but encompassing a range of services including both traditional and more innovative offers may be more helpful. Traditional respite usually means day services offering fixed days and hours when what many carers actually need is choice and options about support at a time when they need it. This also includes the need

for emergency cover when a carer falls ill or needs to attend to a priority in their own lives.

Research shows that, despite the importance of a break from caring from a carer's viewpoint, the evidence around respite services and the type of interventions that are most effective remains inconclusive (Henwood, 2017).

In drawing conclusions about effectiveness, however, it is important to determine what constitutes effectiveness from a carer's perspective and in terms of their satisfaction.

What is clear is that respite support needs to be flexible and work for the carer, but also needs to meet the needs of both person who receives care and support and the carer (whole family approach). Planned respite or replacement care is often not available when carers feel it would be of most benefit. Emergency care providing short term cover for carers in the event of a carer crisis are an essential part of tertiary prevention services. Breaks services should not be commissioned in isolation but considered within the wider context of other support provision, carer benefits and networks.

Conventional models of respite care and the language used to describe respite may also be off-putting to carers (and people who receive care and support). Sometimes a break for a carer can simply be the provision of time and space to be something other than a carer. The Carers Trust also points out that there needs to be more clarity around what constitutes respite care and carers' breaks in mental health – a survey conducted by the Trust in 2014 showed that 54 per cent of professionals, people who receive care and support, and carers did not know how to access respite care (Carers Trust, 2015b).

One of the main areas of concern in relation to dementia care identified by the Older People's Commissioner for Wales is the lack of flexible, enabling and personalised respite support for people looking after someone with dementia. A new study (including a literature review, good practice call and engagement with people living with dementia and carers) will take place early in 2018, with the aim of 'rethinking' respite for well-being from the perspective

of both people living with dementia and their carers (Older People's Commissioner for Wales, 2016).

Carers' organisations in Wales feel that more research is needed in relation to carers' breaks. The Carers Trust has called for a Carer Well-being Fund to provide additional breaks for carers co-ordinated by the third sector (Carers Trust Wales, 2015).

Examples of services providing respite, short breaks and emergency care

A short breaks fund model based on the Scottish Shared Care programme has also been suggested by the Carers Trust Wales, one which is adapted for Wales taking account of the learning gathered from the project implementation in Scotland. Shared Care Scotland operates the fund on behalf of national carers' organisations and the Scottish Government, which funds it on a rolling annual basis. It aims to increase the range and type of short breaks available to carers allowing more flexibility to suit carer needs.

In addition to sitting services, supported leisure and activity holidays, and dedicated short break/respite accommodation, the programme runs a "Respitability" scheme based on a partnership between Scottish carers centres and the hospitality sector whereby businesses in the leisure industry gift short breaks, overnight stays, spa breaks and beauty therapy to offer a different form of respite.

A similar scheme has been offered in Liverpool, where the charity Local Solutions takes a "frugal innovation" approach, i.e. making small changes at comparatively low cost, which can have a big impact. In 2014, they piloted a service targeted at providing respite to carers experiencing stress, social isolation and mental health difficulties. Local hotels led by the Malmaison Liverpool have been signed up by the charity to provide a complimentary monthly bed, breakfast and in some cases, dinner to carers registered at Liverpool Carers Centre and assessed for a respite break. The scheme has potential to expand to other local businesses, travel companies, theatres and restaurants.

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.

The Shared Lives model offers an important alternative to traditional models of care, not only providing older people with the support they need to live as independently as possible and remain part of their communities, but also offering them greater choice in terms of who supports them and the setting in which this support is provided.

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.

Emotional support and engagement

Social isolation and loneliness can be particular challenges for carers. In the latest State of Caring report, 75 per cent of respondents said their caring responsibilities made it hard to maintain friendships and social connections because of lack of time, lack of practical support and the lack of understanding of the impact of caring more generally (Carers UK, 2017). Carers are also twice as likely as non-carers to suffer from poor mental health and depression due to the stresses of their caring role.

Peer support groups, both place-based and online, together with counselling, buddying, befriending and bereavement services have an important preventative role to play in that they supply both practical support and a social connection. Psychosocial activities, such as mindfulness,

meditation, yoga and other body/mind therapies, contribute to well-being and resilience. These type of interventions are increasingly seen as playing an important role in dementia care. A recent systematic review looking at what was needed for interventions to be most effective found that support programmes should include both an educational and therapeutic component (Dickinson et al, 2017).

In recognition of the reality that many carers still need support when their caring role ends, some services have been set up to support former carers with emotional support and bereavement counselling, together with practical advice about issues, such as funeral and care home costs.

Many more innovative interventions, such as carer health checks or resilience-building programmes, have not yet been subject to systematic review but evidence shows contact with others outside the carer's usual social or professional networks is shown to be beneficial in reducing carer stress and social isolation. Gathering and promoting carers' stories are particularly important in highlighting both what matters to carers and as part of the evidence mix when demonstrating the value of particular services.

A twice-monthly male carers' peers support group, provided by the carers' centre and funded by the local authority, was set up in Brighton and Hove when it was recognised that men were not attending the regular services on offer. The focus is primarily social, and transport costs for men with mobility issues are covered by the centre. The group, which holds regular social events and monthly coffee mornings, is supported by a part-time co-ordinator who also offers one-to-one support where this is needed.

Bath and North East Somerset Carers Centre runs a well-being service to help carers maintain their health and well-being, and participate in their local community through the support of Well-being Navigators. The service offers a health and well-being check to identify areas of personal concern, activity support to find suitable local groups and activities, or the option of a Passport to Well-being peer support group meeting over a six-week period to identify small changes that could improve well-being.

Sutton Carers Centre in Surrey provides a specialist service for family carers coping with mental illness. Based on a whole family approach it provides information about diagnosis and treatment, managing medication, dealing with mood and behavioural changes, as well as support to navigate the mental health system and access to activities, providing opportunities to meet other carers of people with mental health issues for peer support.

Employment and training

Carers can face multiple demands none more so than those who combine their caring responsibilities with paid employment. Many carers give up work when they feel they can no longer juggle work and caring, with others reducing their hours or changing to more flexible types of employment to accommodate a better work-life balance. Those who have spent years caring face significant challenges in returning to paid employment when their caring role ends.

The Carers Trust is asking that tools to promote better employment practices, such as the Carers Friendly Employment Recognition Award, be promoted across Wales (Carers Trust, 2015) – and that employers funded by the Welsh Government have flexible carer friendly policies in place including:

- a change of attitude on the part of employers – so that the value of supporting carers to stay in employment is valued and their rights at work are recognised, including time off to care
- access to good quality reliable replacement care services that give them peace of mind while they work
- a benefits system, which supports carers working or studying alongside their caring role.

Practical support in the form of carer education and training has been found to increase carer knowledge, resilience and the capacity of carers to continue with their caring role. This includes:

- planning for and taking on a caring role
- navigating the system, communicating with services, making complaints
- awareness-raising sessions about different long term conditions, for example stroke or dementia, learning about symptoms, medication and behavioural changes

- training in personal care, moving and handling, administering medication
- training for digital literacy to access sources of online support including user forums, completing forms for assessments and other benefits
- coping strategies and resilience techniques, advice on eating healthily, taking exercise, managing stress, improving sleep
- advice on using assistive technologies to support caring.

Training, which offers accreditation or skills transfer recognition, can also help carers seeking employment or volunteering opportunities – employability skills, numeracy, literacy, job applications, interviewing and back to work support. Opportunities to take on a carer representative role and contribute to service development and evaluation of services are valuable in both confidence building and evidence of transferable skills.

Technological support

There is a broad spectrum of telecare products, sensors, monitoring devices, alarms and alerting devices, and smartphone applications that can particularly support working carers and family members caring at a distance, help support the independence of the cared-for person and prevent crisis. For carers, technology can provide peace of mind, allow some time away from caring responsibilities and provide a practical source of support to complement other service provision.

According to Ofcom's 2017 market report, 84 per cent of households in Wales have internet access, 74 per cent of adults use a smartphone and 61 per cent own a tablet with little significant variation between urban and rural populations (Ofcom, 2017). Providing more digitally-based information services for carers, ensuring that carers are provided with appropriate advice about the assistive technology products, and providing training in digital literacy skills for carers can complement the offer of more traditional place-based support services.

Supporting a life alongside caring – good practice example

Carers Leeds

Carers Leeds is an independent charity and award-winning service that has been providing information, advice and support to unpaid adult carers since 1996. Working in partnership with community groups, local businesses and third sector organisations, Carers Leeds provides a holistic network of general and specialised support for carers within the north and south east clinical commissioning group areas of Leeds. The charity utilises professional expertise, as well as the assets of 65 volunteers who offer direct support either in person, online or by telephone.

It provides a range of preventative services for carers to ensure that carers receive the benefits they are entitled to, have access to information about a choice of support services, receive respite from their caring responsibilities, and have opportunities to reduce their social isolation and improve their health.

Carers Leeds sees the importance of identifying carers as an essential part of its role and feels that identifying carers in healthcare settings can be one of the most effective ways of doing this. Its Yellow Card Scheme, which recently won Leeds a national award from the Health Service Journal, encourages the identification of carers in GP practices.

As part of their broader service provision, Carers Leeds was commissioned to deliver a Health and Well-being programme, with the aim of supporting carers to take care of their own physical and emotional health. Through one-to-one support

and raising wider awareness of issues, carers are encouraged by health and well-being support workers to eat more healthily, be more physically active, cut down on alcohol and smoking, manage stress and anxiety, and be more socially connected (Bunyan, Woodall & Raine, 2017). One of the more notable outcomes from the evaluation was that participating individuals who were previously unable to self-identify as carers now acknowledged the importance of taking care of their own health to support their cared-for person.

Carers Leeds organises more than 30 individual carer support groups providing peer support, social activities and short breaks. Specialist services are offered to carers of people with mental health issues, substance misuse, dementia and young carers (aged 16-25), BME carers and LGBTQ carers.

Carers Leeds works in partnership with other providers in Leeds, for example, with Touchstone, a community mental health housing project, the local Age UK Hospital2Home project, and health services, particularly in primary care.

It attributes its success to being well-networked across the city, having established good relationships with commissioners from the local authority and clinical commissioning groups, and to their commitment to a shared vision. They work in a structured way to ensure consistency of practice.

They measure what matters to carers using the Triangle “Carers Outcome Star”, an evidence-based tool for measuring and supporting change, and tailoring other established measures (ASCOF, ASCOT) to capture outcomes from different aspects of the service.

Evaluating what works for carers

Evaluating what works for carers

- measures of success for carer support include feeling acknowledged and valued, being able to pursue what is important to them and being able to make the most of their lives, having a strong voice and being able to influence services that affect them – these can be measured using carer outcome measures around the impact of caring, carer quality of life, experience and quality of life, and carer competency
- commissioned services should demonstrably improve carer outcomes in line with the Social Services and Well-being (Wales) Act 2014 definition of well-being (the eight domains of the Welsh Government well-being statement)
- there is an acknowledged need for improved data collection, better monitoring and evaluation of support – and more evidence about what works and for whom
- the absence of robust longitudinal datasets weakens the potential evidence of what works for carers – the population needs assessment includes a section on carer data, but there is no household survey type information on carers in Wales as there is in England
- evaluations of pilot programmes need to be better designed based on change logic models and clarity around the different hypotheses in relation to the effects of interventions.

Carer awareness – social care workforce

What do carers want from carer support professionals?

- people who understand the carer role, who listen and are non-judgemental
- clear, consistent, co-ordinated information and support across professional boundaries and organisations
- professionals who are reliable, knowledgeable and trustworthy
- pro-active engagement and inclusion with carers, including information sharing (this can particularly be a challenge for carers of people with mental health issues where policy and protocols around confidentiality and information sharing need to be in place as part of good practice)
- training that provides carers with a good understanding of how to work with different people and respond to specific needs arising from specific conditions, such as dementia, multiple sclerosis, mental health diagnoses
- the triangle of care model, developed by Carers Trust, is being reviewed by a number of health boards in Wales – the model was initially developed by carers and professionals seeking to improve carer engagement in acute inpatient services and is based on research into what carers of people with mental health services needed from service providers
- RiPFA has recently produced an online resource to support social workers working with carers: carers.ripfa.org.uk

There is scope for more workforce development in relation to carer awareness and support, for working with carers, identifying them and their needs, being aware of what is already available (local asset mapping), working with carers to co-produce solutions, and evaluate service effectiveness.

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Appendix B: Methodology

Thanks to Sheila Lyons at Social Care Wales for her support in identifying key documents and contacts.

Telephone/email interviews

Kim Sparrey, Carers Services Development Manager Monmouthshire and COLIN lead

Peter Martin, Senior Policy Advisor, Hafal

Simon Hatch, Director, Carers Trust Wales

Claire Morgan, Director, Carers Wales

Literature and desk research search – key themes and search terms

Carer populations (adults)

- spouse and partner
- adult children caring for parents
- relatives, family
- gender
- parent carers of disabled children
- dual and or “sandwich” carers
- rural carers

Types of care

- older people
- dementia
- mental health
- children with disabilities
- learning disabilities
- cancer, stroke and other long-term conditions
- end of life
- multiple carer roles

Impact of caring

- the caring relationship
- carer transitions
- burdens/satisfaction of caring
- resilience
- financial costs
- well-being – physical and psychological, health, diet, exercise
- social isolation and loneliness

Support and interventions

- preventative approaches in social care
- identifying and recognising carers
- carers' needs and assessment
- direct payments, personalisation
- commissioning and cost-effectiveness of carer support
- respite/short breaks
- carers in employment
- health and care services, primary care, hospital care, reablement mental health services
- community support – dementia communities
- voluntary sector support
- transitions – e.g cared for child to adult, end of life/palliative caring
- training for carers
- workforce

Literature searches – Social Care Online database

Searches undertaken: September to November 2017.

Material published since: 2012, in the English language.



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