Herefordshire Council

NHS
Herefordshire
Clinical Commissioning Group

A Joint Carers Strategy for Herefordshire

2017 – 2021

***Co-produced with and for carers**, the people who look after family members, partners and close friends, because they themselves are family members, partners and close friends.*

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Acknowledgements

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Foreword

Unpaid carers are one of Herefordshire's most valuable assets and play a crucial role within the county's health and social care sector.

We live in times when public services are changing significantly. We recognise a collaborative approach to developing transformational change and delivering services is fundamental to keeping residents and carers healthy and well. As a result, this strategy, which has been developed by Herefordshire Council and Herefordshire Clinical Commissioning Group, has been co-produced with carers to both encapsulate their aspirations and recognise the challenges which come with being a carer.

It seeks to mitigate the challenges carers face by changing the way that universal services are provided. The delivery of the strategy will see a redesigned and newly commissioned carers' service that will supplement existing universal services. Working in this way will help carers to find information and support within their own communities and, at the same time, provide extra resource where carers have a higher level of need.

The strategy is aligned to both Herefordshire Council's Corporate Plan and Herefordshire Clinical Commissioning Group's Five Year Strategic Plan. Both plans emphasise the importance of active prevention by changing the way services are delivered and keeping people well within their communities. Seamless and innovative ways of working, and the use of improved technology and resources within Herefordshire, will help us continue our collaborative work to support carers and keep them well.

Part one - The shared vision

Our shared vision is that carers are recognised and valued, able to keep well and live their own life.

Recognised

- I am recognised as a carer
- I have information provided to me proactively by services
- I understand how to access support
- Services meet my aspirations and needs
- Information is provided in a way which allows me to fulfil my caring role

Valued

- My aspirations and needs are heard and help to shape assessments
- My experience and knowledge is valued when assessing or providing care to the person I care for
- My experiences are valued in shaping how services are designed and delivered

Able to have their own life and keep well

- I am able to balance my caring role and my own life
- I am confident to fulfil my caring role safely
- I am able to look after my own health needs
- I am able to access my community
- I have to access work and education and can fulfil my aspirations
- I can maintain my work or education
- I am able to manage financially

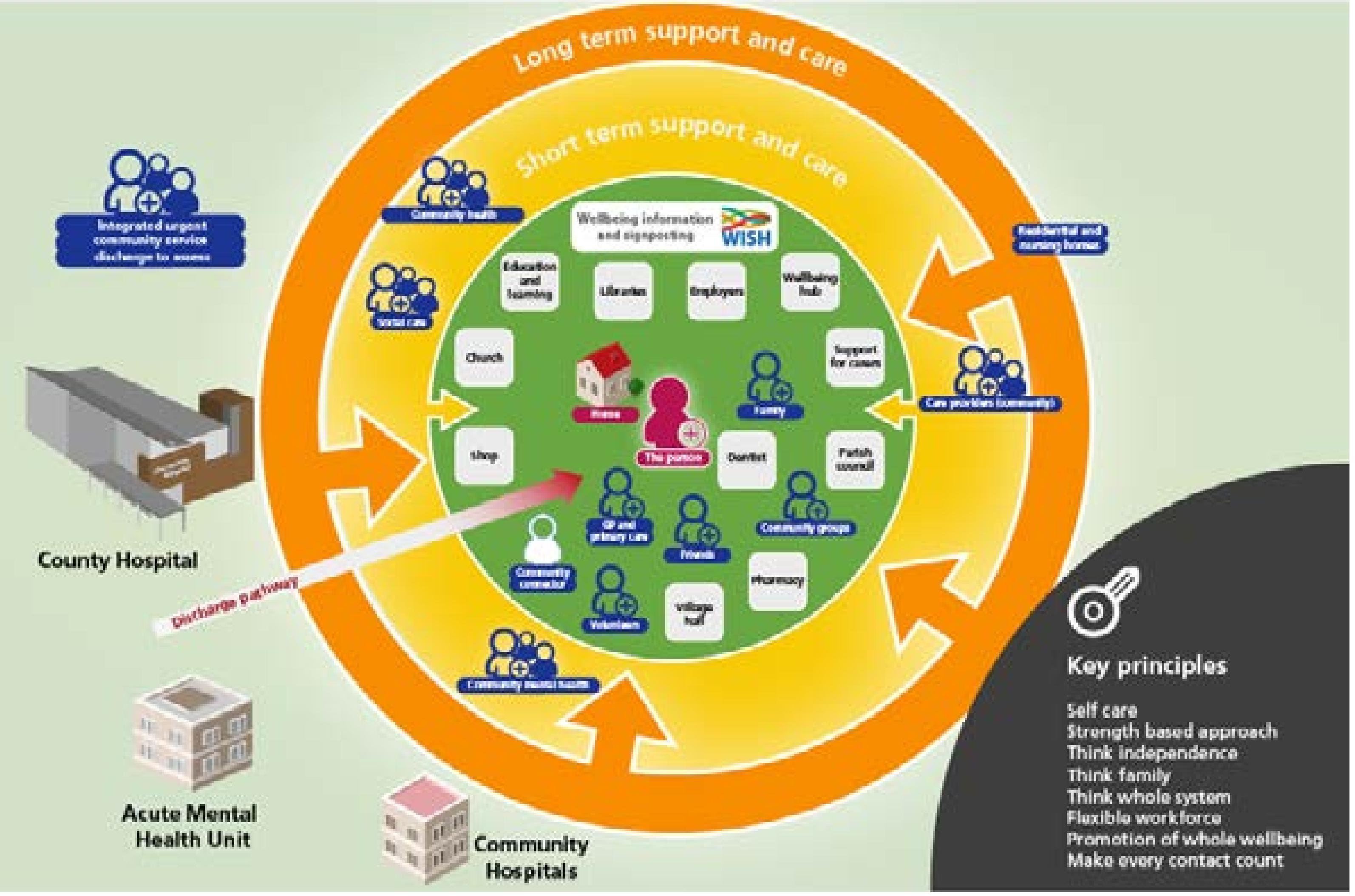
The vision has been developed with carers as a means of articulating that carers are unique but with similar aspirations, although some are more specific to certain groups of carers. For example, young carers are likely to have different aspirations to older carers.

The vision has informed six priorities:

- Information, advice and signposting
- Identifying carers
- Carers' knowledge, skills and employment
- Access to universal services
- Networking and mutual support
- Assessment and support

This also fits with Herefordshire Council's Health and Wellbeing Strategy and Adults Wellbeing Plan, which is visually represented in 'The Blueprint' on the next page.

The Blueprint



The Blueprint illustrates how adults, including carers, habitually use their own families and community as the norm for support and do not want to become reliant upon services to assist them. However, where carers' needs and aspirations are unmet, statutory services will be used to facilitate carers' access to the community and ensure their health and wellbeing remains the central focus.

The principles of The Blueprint are also intended to encompass the cared for person. Carers meet all or part of the cared for person's needs and it is widely acknowledged that the contribution of unpaid carers would otherwise have to be met by the social care and health care system at the cost of a significant amount of time and money. A report from Carers UK and the University of Sheffield, published in 2015, revealed that unpaid carers in the UK save the state £132 billion a year.

Whole system changes will assist carers to meet their needs and aspirations. The limited resources available to commission services for carers will be used strategically to have the widest impact possible, for the largest group of carers. This will be achieved by seeking to ensure support from universal services and carers' communities, enabling effective use of resource in supporting the aspirations of a growing population of carers.

Services provided to the cared for person need to be focussed on maintaining the independence of both themselves and their carer, while bolstering their strengths by:

- Facilitating access to the community
- Meeting any unmet needs to ensure the cared for person and carer can have fulfilled lives within their communities, where possible
- Enabling young carers to lead lives of their own and access opportunities available to other children

Each carer is unique, both as an individual and in their caring role. For the effective consideration of the challenges faced and shaping the vision and priorities, carers have been themed into a number of groups, illustrated in section 4.1. It is recognised that carers will often fit into more than one group.

Part two - The priorities

The priorities have emerged clearly and consistently from co-production and engagement with carers, detailed in section 4 below and reflect the issues and concerns they've expressed. An implementation plan will be developed and agreed during 2017, which will set out actions to realise the six priorities.

The strategy identifies the particular importance of identifying and supporting young carers and Herefordshire Council recognises its statutory duties to them. The significance and relevance of supporting young carers is set out in relation to each of the following six priorities.

Priority 1

Information, advice and signposting

This includes information on social care and health issues, signposting to services, availability of local community support and specialist information for carers. It does not include legal or quasi legal advice

Carers' expectations and aspirations

Carers rightly expect to be able to receive the right care and support for those they care for and the right support for themselves.

Carers want a credible and consistent source of local information and advice upon which they can rely.

Carers expect information and advice to be accessible in a variety of ways, 24 hours a day. Some carers also want to talk to someone in order to get the information and advice they need.

Carers need to be supported to understand the detail and implications of the cared for person's needs at the point of diagnosis.

Young carers may not have informed expectations of what information and advice should be available to them.

Young carers may expect to get information and advice through a wider range of in-person and technological means.

Carers want access to information to help them live their own life as well as achieve the best outcomes for the cared for person.

Other carers and former carers are a significant and uniquely valuable source of information and advice for other carers.

Challenges and barriers

Multiple services are funded to provide information and advice for carers. This is expensive and leads to inconsistency and inequity.

Professionals have access to different information sources than carers and often don't know how to signpost and advise carers. Many professionals are not yet using WISH (Wellbeing Information and Signposting for Herefordshire).

WISH, Herefordshire's universal offer of information, advice and signposting, requires some improvement and is not sufficiently known among carers. Currently it carries insufficient content and information for carers.

Young carers have to rely more than other carers on different professionals, including those in schools and colleges or professional services to provide the right information and advice.

Carers are seldom given the information they need to fully understand the implications of diagnoses and health conditions.

Some carers have smaller informal support groups, but there is limited access to networking opportunities.

Not all carers are able or want to use the internet and broadband connection remains very difficult for some people in rural areas.

Young carers make limited use of the online and interactive platforms currently available to them.

What needs to happen

Promote and invest in WISH to establish it as the carers' information, signposting and advice service, alongside scheduled upgrades and improvements.

Continue work to embed WISH in the response of universal services and require contracted health and social care providers generally to identify carers and encourage them to use WISH.

Commission a service to offer advice and support to carers, providing a first contact point which promotes self determination and independence among carers.

Ensure that identification and registration for carers are commissioned in such a way as to connect effectively with WISH and carers' first point of contact.

Establish facilities on WISH and elsewhere for social media and interactive content.

Work in partnership with the Fastershire project to ensure broadband access for vulnerable carers in rural areas.

Find ways to co-produce with young carers to support their interactive networking and mutual support in the most welcome ways.

Health professionals will provide information about the diagnosis of the cared for person to the carer and signpost to services which can provide advice and support.

Key outcomes

- Comprehensive information and advice is available online and through communities, including schools and colleges, and for people not using the internet. This is supported by extended content and improved performance on the WISH website.
- Improved access to online support and interaction including internet access for isolated or vulnerable carers.
- Professionals can easily access information and signposting for carers whom they are supporting.

Ellie's story

Ellie is 15 and cares for her mum and younger sister. She doesn't have many friends and doesn't like people coming round to her home, in case her mum's having a bad day and is acting strangely – people just don't understand. This makes her feel isolated and although she gets to talk to other young carers at events organised by her carers support group, she'd like to be able to mix with other young people too. Her school knows about her caring role, but doesn't talk to her about it. She worries about homework and keeping on top of her studies.

What difference could this priority make?

Ellie would be able to find out more about accessing activities and events in her area for young people through WISH. She could also share her caring experiences, questions and worries with other young carers through discussion boards hosted by WISH and other social media platforms.

The information on WISH could help boost pastoral support provided by the school and give them a better understanding of the pressure Ellie is under as a carer.

Priority 2

Identifying carers

Carers identifying themselves in order to obtain appropriate information, advice, support and entitlements

Carers' expectations and aspirations

Carers often do not identify themselves as a carer, either not perceiving the role they fulfil as caring or preferring to identify themselves as a family member or friend.

Young carers have a particular right to expect that they will be recognised and supported by public services.

Young carers may need to be convinced of the benefits of identification and registration.

Carers do expect professionals to acknowledge the pressures upon them and the impact this has on themselves and the person they care for, whether they self-identify or not.

Carers want professionals and services to provide the information, support and opportunities available to them and prefer these to be joined up.

Carers are often happy to register and identify as a carer when the benefits of doing so are clear.

5,431 carers have subscribed to the Herefordshire Carers Support (HCS) scheme (figure reported March 2017), equating to between 16% and 24% of all carers in Herefordshire. This supports self-identification and makes carers aware of the current range of support offered by HCS.

Challenges and barriers

There is no carers register as such in Herefordshire, which allows public bodies to contact carers directly, analyse need and improve services.

Until carers identify themselves, they are unlikely to get the support they may need.

Young carers may choose not to identify as a carer. Identification and recognition of young carers varies considerably among professionals and across schools and other services.

Many carers report that until they identified themselves as a carer, they were unaware of a range of entitlements and opportunities available to them and the person they care for.

Current arrangements for identification may not give carers access to all the support and services available.

Proposed improvements in information and advice for carers and the management of urgent care and hospital discharge will only be fully effective if linked to identification and registration.

Unless identification and registration is linked to public services and their assessment and case management activity, carers will continue to be affected by duplication of process and lack of recognition from some professionals.

What needs to happen

Promote awareness of early identification of carers amongst professionals and diverse agencies through information and training.

Re-launch a carers register, exploring the potential to register those carers already known to existing services.

Undertake specific work to secure the confidence of young carers in future identification and registration arrangements.

Explore the potential for linking identification with information and advice for carers.

Integrate carer identification with the offer of Carer's Emergency Cards and specific support schemes relating to urgent care and emergency support.

Ensure that emergency arrangements consider the specific needs of young carers.

Ensure optimum level of integration of a register with council and NHS case management systems, including a secure access database.

Make specific arrangements relating to the identification and assessment of young carers.

Devise data protection and information governance provisions, including effective opt-out of data sharing for carers.

Key outcomes

- Carers have immediate and effective access to information and signposting when they have self-identified.

- Those working with children who may be young carers are able to identify, support and signpost. Young carers continue to identify and register as carers.

- Optimum numbers of carers are registered, building on those already identified.

Judith's story

Judith is nearly 80 and cares for her husband Tony who acquired a brain injury after falling in their garden a few years ago. She does not see herself as a carer, has no transport and is socially isolated, preferring to keep herself to herself. Judith's GP understands the family very well and is concerned for Judith as a carer. She hasn't been sleeping very well and although she gets some help with Tony, her own health is fragile. She had a stroke a couple of years ago and gets tired very easily. If anything should happen to Judith, Tony would become even more vulnerable, as he would be unable to care for himself.

What difference could this priority make?

Judith's health and wellbeing has an impact on her husband's care. Registering as a carer on a shared carers register has the potential to allow her GP, hospital, local carer support group, social services and other professionals to recognise her as a carer and provide multi-agency, cohesive support. It would also flag up the consequences should she become ill or be admitted to hospital.

If anything were to happen to Tony, she would be part of a carer network and able to access information, advice, support and activities to help her stay healthy and stop her from being socially isolated.

Priority 3

Carers' knowledge, skills and employment

Carers have a variety of skills and experience and often develop significant expertise through their caring role. Carers sometimes need support to maintain or resume their career

Carers' expectations and aspirations

Carers frequently acquire knowledge and expertise around health and social care through first hand experience of the system. They would like this to be respected and valued.

Carers offer insight into the quality of different services and organisations and other issues. They should expect to be meaningfully involved in designing and reviewing services.

Young carers are uniquely placed to comment on a wide variety of services for young people.

Carers want to retain the skills and qualifications they had before becoming a carer and to maintain their careers.

Carers need to retain employment in order to sustain their income, social networks, confidence and lifestyle.

Young carers have a right to achieve in education and develop as children despite their caring role.

Many carers are keen to support other carers and may be in a position to assist each other's training or career.

Challenges and barriers

Many carers do not identify themselves as a carer or are not recognised by public bodies; as a result only a small group of carers tend to be involved in everything.

Carers have significant demands on their availability and would find it difficult to participate in decision making unless creativity and flexibility were shown.

Carers can sometimes have conflicts of interest with regard to some services or issues.

Carers may need appropriate training or support to enable them to participate.

Young carers may be reluctant to be involved in questioning or challenging some services. A considered approach may be needed to ensure their meaningful participation.

Given the demands of their caring role, some carers may require a review or extension of support in order to sustain employment.

Carers are not always in contact with other carers and may face barriers to social contact or networking for mutual support.

The cared for person may not give consent for their information to be shared with their carer.

What needs to happen

An agreed approach amongst commissioning organisations to the increased recognition and participation of carers in the design, procurement, and review of social care and health services.

A flexible approach to participation needs to be facilitated to give carers the opportunity to take part within the constraints of their daily lives.

A new approach to involving young carers routinely in the council's strategic engagement with children and young people.

Carers enabled to provide their user experiences online and via a range of training and learning events.

A review and action plan for supporting educational achievement by young carers.

A continuing programme of training opportunities for carers associated with the caring role.

Ensure consideration of carers' employment or education needs in any strength based assessments.

Use the Herefordshire and Worcestershire Sustainability and Transformation Partnership (STP), One Herefordshire, Marches Local Enterprise Partnership (LEP) and other partnerships to promote supportive and fair work places for carers.

Work towards access to an employment plan and training for carers with the Department for Work and Pensions (DWP) and other partners.

A sensitive and balanced approach by universal services if the cared for person does not wish for their information to be passed to their carer.

Key outcomes

- Carers who routinely feel recognised and respected, with their views sought and valued.
- Carers meaningfully involved in the review and design of health and care services, where this is appropriate.
- Young carers are confident and enabled to participate in the review of services and other decision making.
- Herefordshire employers are signed up to a commitment to recognising and valuing carers in the workforce.

John's story

John found it difficult to juggle caring for his wife, looking after his very young children and holding down a job. When his wife's condition deteriorated, he took redundancy and became a full time carer. His wife kept being admitted to hospital, but there was never any discharge plan when she came home and he was not involved or listened to when her needs were being discussed. Sadly, she died in pain at home. John finds this really difficult to live with and he is struggling to reintegrate into society.

What difference could this priority make?

John would have been recognised as his wife's carer and respected by the professionals. They would have listened to him and involved him in planning hospital discharges and, finally, in planning palliative care for her, so that she could have passed away peacefully.

If his employers had been more understanding of and recognised and valued his role as a carer, they may have been able to help him retain some kind of employment during his wife's illness. They could also help John reintegrate into the workplace, now his wife has passed away, giving him the chance to regain self-esteem and become socially active again.

Priority 4

Access to universal services

Universal services include schools, colleges, GPs, ambulance service, accident and emergency services, childcare, leisure services, welfare and benefits advice services, libraries and others. They are services available to anyone who needs them without any assessment or eligibility process

Carers' expectations and aspirations

Carers want to live their own life on their own terms and like anyone else, notwithstanding their caring role.

Carers want to remain in good health and have a decent quality of life.

Young carers want to have the same opportunities as other young people, to have a fulfilled childhood and achieve their potential.

Carers can reasonably expect to have access in the same way and to the same extent as others to schools, childcare, GP services, health visitors, ambulance services, libraries, accident and emergency help, information and advice.

Since the needs of the carer and cared for person are inextricably linked, carers can reasonably expect universal services to recognise and respond to their needs when providing a service to the cared for person.

Young carers should feel confident that their needs will be identified and met before they reach crisis.

Challenges and barriers

Typically, carers have enormous demands on their time and face significant stress and other pressures, which affect their daily lives in many ways.

Many carers experience relatively poor health outcomes and restricted access to education, training and leisure opportunities.

Some NHS and other services do have reasonable adjustment policies, but these may not specifically consider carers.

Only some services may have organised training around carers for staff and some may lack insight into what it is like to try and use their services as a carer.

Carers particularly report inconsistencies across the health system and are often frustrated by a lack of recognition of their role or status as carers.

There is a tendency for carers, including young carers, to be recognised and supported only at the point of crisis.

What needs to happen

Universal services can demonstrate that they are carer aware in planning services and responding to individuals.

Specific research and analysis is required of carers' health needs and inequalities across public health, social care and health commissioning.

A joint plan between commissioning agencies to promote and monitor reasonable adjustments across NHS, universal and wider public services in Herefordshire.

Promotional material and e-learning relating to carers needs to be shared with universal service providers with whole system agreement and process of early identification of carers at first contact.

In the re-commissioning of carer support services, resources will be directed towards challenging, advising and training universal services in best practice around reasonable adjustments and helping carers navigate through systems and services.

Consider the feasibility of including carers as an additional group with protected characteristics under the Equality Act 2010.

Meaningful involvement of carers with Herefordshire Clinical Commissioning Group and Herefordshire Council in design, procurement, monitoring and review of universal and other contracted services.

Ensure appropriate health checks are available for young carers and that all NHS providers can recognise young carers and respond to their needs, especially when treating the cared for person.

Key outcomes

- Fairer and more effective access to universal services for carers, including young carers.
- Carers manage their own health needs appropriately and feel enabled to get help and advice.
- Key indicators are agreed for measuring the improvement in carers' health, which are consistent with national data.
- Regular health checks for young carers and health services identifying their needs at every point of contact.

Carol's story

Carol cares for her 18 year old son Callum, who has autism. He was supported throughout his school years, but now he's an adult, he is finding it difficult to access universal services and Carol worries about his future. All her energy goes into trying to get support for him so he can live a happy and independent life. Carol has her own health problems; she suffers from type 2 diabetes, which is not helped by her lifestyle choices. She is obese, smokes and is physically inactive. She is not managing her diabetes well and she knows she needs some help with this, but struggles to make appointments with her GP, because the practice is unable to offer times that fit in with her caring role.

What difference could this priority make?

If the GP practice recognised Carol as a carer, allowances could be made under the booking system to give her more control and choice over appointment times. The practice could also share this knowledge and understanding if any referrals were made on Carol's behalf to other health professionals, such as a healthy lifestyle trainer.

Priority 5

Networking and mutual support

Carers are often the best source of information, ideas and support for other carers and technology presents opportunities for carers to form and sustain networks

Carers' expectations and aspirations

Carers want and expect the same social opportunities as everyone else and may particularly value social interaction and support.

Carers should reasonably expect professionals and public services to recognise the pressures on their lifestyle and support networks.

Carers often establish new social contacts through the person they care for or other carers and the most effective mutual support networks are typically among carers of similar age or needs. Carers value the mutual help and support they can achieve with other carers and often find them the most relevant and useful source of information and advice. There are examples of dynamic and effective mutual support groups and networks which rely on little or no support from professionals or carers services.

Social media and technology can enable mutual support and networking in a variety of ways so that carers can form and sustain their own networks, especially in rural areas.

Challenges and barriers

Carers can become isolated owing to various pressures arising from their caring role.

Some carers may need practical or personal support to re-establish social networks. This may not be consistently recognised and addressed by professionals.

There is a risk of social and support networks stagnating and not enabling people to learn, become independent and progress.

Support groups, continuously supported by paid workers, may become unaffordable and unsustainable.

Young and older carers and carers in rural areas are particularly vulnerable to isolation and loss of social and support networks. This can be exacerbated by poor access to broadband and technology.

What needs to happen

Promote ideas and opportunities for mutual support and social networks through information and signposting.

Identify and promote best practice in forming and sustaining mutual support networks.

Identify carers with poor access to broadband and seek improvements via the Fastershire programme.

Establish new places online for carers to interact, share information and support each other.

Provide professional support to connect carers and initial development of new groups and networks.

Identify young carers and others who are particularly vulnerable to social isolation and providing support.

Provide support to leaders of groups and networks. Value the experience and knowledge of groups and help publicise them and their achievements through WISH and other means.

Key outcomes

- Carers have access to a variety of networks and mutual support to suit their interests and needs.
- Fewer carers experience social isolation through improved access to technology and mutual support.
- Effective connections between WISH, self-identification and mutual support and networking.

Shona's story

Shona cares for her eight year old son Ben, who has a moderate learning disability, and her 22 year old son Harry, who has ME. She doesn't get much time to herself; her day revolves around taking Ben to and from school and caring for Harry. She is desperate to have some 'me time' and would like to meet other mums, network more and just be able to go to a coffee morning or two, where people understand what it's like living with a disability.

What difference could this priority make?
Shona could meet other people at coffee mornings and events taking place in her local community. She could also get involved in online chats with other parents who have children with disabilities, make new friends, share information and feel less isolated.

Priority 6

Assessment and support

Carers have a statutory right to an assessment. They also contribute routinely to assessments of the person they care for. Some carers will require specific support to continue to fulfil their caring role

Carers' expectations and aspirations

Generally carers would prefer to provide complex and detailed information only once and support the sharing of information among teams and agencies.

Carers expect that the dignity and respect for privacy accorded to them will be equal to that accorded to the person they care for during assessment processes.

Carers in general have statutory rights to an assessment under the Care Act 2014. Young carers' assessments are provided for in the Care Act 2014 and Children Act 1989 (as amended).

Young carers have specific entitlement to assessments, including transition assessments and support planning.

Carers are essential contributors to assessments in relation to the person they care for.

Young carers need and expect coherent planning around different types of assessment and delivery of the resulting support.

Carers, including young carers, have a right to expect that any safeguarding concerns will be handled appropriately and with effective communication, whether the concern relates to the cared for person or the carer.

Carers may seek support of different kinds from different people or organisations and some may expect ongoing personal support for themselves.

Challenges and barriers

Carers are often required to participate in numerous assessments and many are confused about the status and function of assessments and the rights of the carer and cared for person.

Many carers feel they do not get the level or type of support they need to continue in their caring role.

Carers own health needs as patients are assessed routinely by the NHS through GPs, community health teams and in acute care, often without reference to their caring activity.

Carers often feel that the significance of their caring role is not recognised or appreciated during assessments.

Specific attention is required around good practice in health assessments of young carers.

The carer's contribution to assessments and reviews of the cared for person is not consistently valued or recorded.

Professionals may not always know when it is appropriate to offer a carers' assessment, and the process of support planning and options are not always explained appropriately.

Young carers often face individual challenges which are not obviously linked to their caring role. These challenges need to be acknowledged when undertaking assessments or planning support.

Children who provide care for parents and siblings, where their parents are abusing substances, need special consideration due to potentially unmanaged risks and fluctuating needs.

Occasionally, there may be divergence between the needs and interests of the cared for person and the carer, which may require a separation of the assessment processes and other arrangements to be made. This may include circumstances where there is a safeguarding investigation, relating to either the carer or cared for person – further information is provided below in 'Assessments and safeguarding'. Some carers seek continuing support, such as emotional support from sources which cannot provide it, because they lack either the expertise or the time and money.

What needs to happen

Ensure the needs of carers are identified and responded to with appropriate support, whether through a carers' assessment or other means.

Ensure the benefit and purpose of statutory and other assessments are made clear.

Enable carers and professionals to maintain open and continuing dialogue to ensure the needs of the cared for person are met.

Use training and awareness raising with professionals to build upon the delivery of carer assessments and support planning under the Care Act.

The new adult social care pathway places significant emphasis on the role, contribution and strengths of the carer and will involve them naturally in the process.

Carers are supported in such a way to maximise their independence and minimise long term dependence upon formal or specialist services.

Promotion of mutual support networks among carers, rather than ongoing professional support.

Develop protocols for participation of carers in clinical assessments and reviews, including documentation and information sharing. Review of clinical practice in assessing and treating young carers.

Seek funding to support participation of and focus on carers within hospital discharge planning.

Review of support planning and delivery for young carers and ensure alignment to appropriate assessment, including transition assessments.

Engage young carers in evaluating assessments and designing options for support.

Key outcomes

- All carers requiring assessment and/or support planning receive them appropriately.
- Carers feel their views and needs have been listened to and responded to effectively and appropriately, whether or not by way of a formal assessment process.
- All young carers identified receive assessment and support planning consistent with statutory requirements, including transition assessments.
- Evidence of the health needs of young carers are being consistently identified and met.
- Carers are active participants in hospital discharge planning following strengths and risk based models.
- The strengths of carers are recognised during assessments. Carers are primarily connected to sources of support within their local community. Where their needs remain unmet, they have access to a support service specifically for carers.

Brenda's story

Brenda is an older disabled carer and needs a wheelchair to get around. Her husband has recently been diagnosed with dementia and this is putting significant pressure on their ability to manage at home. Her husband has been assessed, but there is no home care support available because they exceed the financial threshold and Brenda is there to look after him. Brenda receives a direct payment to help meet her needs as a person living with a disability, but not as a carer.

What difference could this priority make?

Brenda and her husband could be assessed together to see how they can support each other and where they need additional help. Without Brenda, her husband would not be able to safely live at home. A joint assessment would recognise that she needs help to manage her new caring role as well as her own disability. A strengths based assessment and support plan by a community broker would enable support for the couple based on what they can and like to do and what is on offer in their local community.

Assessments and safeguarding

The Care Act 2014 defines adult safeguarding as protecting an adult's right to live in safety, free from abuse and neglect.

Abuse or neglect are frightening terms and amount to a sensitive issue, but neither has to be deliberate, malicious or planned. There is a clear difference between unintentional harm caused inadvertently and a deliberate act of either abuse or omission.

In cases where unintentional harm has occurred, this may be due to lack of knowledge or because the carer may also be an adult with care and support needs. In this situation, the aim of assessments and any associated safeguarding work will be to address risk. It may be appropriate to help the carer to provide support in order to decrease the risk of further harm to the person they are caring for.

Assessment of both the carer and the adult they care for must include consideration of their wellbeing. The assessment is an important opportunity to consider whether it would be possible to provide information or support that prevents abuse or neglect from occurring. For example, by providing training to the carer or supporting them to care more safely.

If a carer speaks out about abuse or neglect, it is essential they are listened to and that, where appropriate, a safeguarding enquiry is undertaken and other agencies are involved as appropriate.

Part three - Developing the strategy

This strategy has been co-produced with carers, along with other stakeholders. During 2017, more than 150 unpaid Herefordshire carers have contributed to the information and ideas in the strategy, individually and in groups. Commissioners have gone to carers and engaged with them, wherever they are and in whatever way carers chose, to gather their views. The starting point for discussion was the clear messages about what carers need, collected since 2015 through carer consultation. This has been built upon to develop the priorities and proposals within this strategy.
The co-production process will continue as the strategy is finalised and throughout its implementation and the re-commissioning of services.

3.1. Understanding carers' views and experiences

Carers wish to be able to fulfil their caring role while also being able to have their own life and keep well. It is as important to carers as it is to the council and NHS that the cared for person and carer are able to remain living in their local community for as long as they are able.

3.2 Themes common to all groups of carers

- Carers often do not identify themselves as a carer, but rather as a loving relative or friend.
- Those carers who do not necessarily identify as a carer may have been coping without support, but for some this is built on fragile foundations.
- Universal services sometimes fail to identify carers, adapt their services or share information, even within their own departments.
- Carers are often only identified at the point of crisis.
- Information and advice is disjointed, complex and inconsistent, often with a sense of not knowing where to start.
- There is a sense of fear about what would happen to the cared for person if the carer was no longer able to fulfil their carer role, for example, if they were suddenly taken ill.
- Some carers feel they are socially isolated and unable to take time for themselves.
- Carers often neglect their own health and wellbeing as their lives are dominated by the person they care for. They may be too exhausted to address their own needs.
- Carers lose income due to having to reduce their hours or miss potential career development opportunities, which also has a negative impact upon their pension.
- Carers struggle to balance education or training opportunities with their caring role.
- Carers feel they are not respected or listened to by professionals.
- There is poor understanding of the carer assessment. Assumptions are made that the process is complex and draining for potentially limited or no help.
- The level of support carers need is dependent upon their own circumstances, their support network, the person they care for and their perception of services.
- Carers are fearful of reductions in services and that respite, day care opportunities, mutual support groups and other provisions, which provide a break from caring, will be cut back or removed.
- Carers want to be helped to participate in the design and delivery of services at an individual, operational and strategic level.

Black and minority ethnic carers

Carers from black and ethnic minorities may face additional challenges over and above those faced by carers generally. This may include cultural barriers to seeking help and support.

In Herefordshire, the largest ethnic minority group is the Gypsy, Roma, Traveller (GRT) community. There is extensive national research to suggest that members of this community experience health inequalities. However, there is little intelligence locally on the impact of caring within the GRT community. Further work is needed to identify the reasons for inequalities, so that services can be managed to ensure the needs of all communities are met equally.

Social isolation

Carers often report becoming isolated as a result of their caring responsibilities. They attribute this to a lack of understanding about their caring role, as well as leaving paid work and being unable to take time off from caring, resulting in losing touch with friends, colleagues and family members.

The 2015 Carers UK 'Alone and Caring report' gave the following key findings:

- 8 in 10 (83%) carers have felt lonely or socially isolated as a result of their caring responsibilities
- 6 in 10 (57%) carers have lost touch with friends and family as a result of caring and nearly half (49%) of carers say they have experienced difficulties in their relationship with their partner because of their caring role
- 4 in 10 (38%) carers in full-time employment have felt isolated from other people at work because of their caring responsibilities
- Carers who have reached breaking point as a result of caring, are twice as likely to say that they are socially isolated because they are unable to leave the house and are also more likely to have experienced depression as a result of caring.

Health

Without the right support in place, carers often find their own health and wellbeing suffering as a result of the care they provide. By putting their loved one first, carers can put their own needs last, struggling to find time to exercise, eat healthy meals, see friends and family, or even see the doctor. This year's survey has again found that this is having a knock-on impact on carers' physical health, mental health, and relationships with others.

82% of carers said that caring has had a negative impact on their health. Three quarters (74%) of carers find it difficult to get a good night's sleep, while nearly half (47%) struggle to maintain a balanced diet. Four in ten (41%) have experienced an injury or their physical health has suffered as a result of caring.

(The 2015 Carers UK 'State of Caring Report')

3.3 Challenges for specific groups of carers

Beyond the common themes identified, there are additional challenges which are faced specifically by certain groups of carers:

- Young and young adult carers
- Working carers
- Older carers 65+
- Former carers
- Specific condition carers

Young / Young adult carers

Young carers in Herefordshire said that:

- They are socially isolated as a result of caring
- Their educational establishment does not recognise their caring role or make allowances for poor / late attendance, homework, tiredness etc
- They want their educational establishment to recognise and support them whilst respecting the need for confidentiality, as they do not wish to be labelled
- They need an outlet for socialising away from their family
- Services provided to them, such as counselling or recreational activities, are dependent on funding
- Services are often inconsistent or running late, which makes the young carer feel devalued
- They are directly affected by changes in services for the person they care for. For example, one family lost work due to caring for their disabled child which resulted in homelessness. They were moved to a different area, forcing the two other young siblings to move schools
- There is a place for emotional support from services to engage young carers and build trust with them and their families
- It is important to help them build up social networks and overcome barriers, such as transport or financial constraints

Young carers - the facts:

In 2013, the Children's Society completed a study entitled 'Hidden from view: The experiences of young carers in England'. Some of the findings were:

- One in 12 young carers are caring for more than 15 hours per week and around one in 20 misses school because of their caring responsibilities
- Young carers are 1.5 times more likely than their peers to be from black, Asian or minority ethnic communities and are twice as likely to not speak English as their first language
- Young carers are 1.5 times more likely than their peers to have a special educational need or a disability
- The average annual income for families with a young carer is £5,000 less than families who do not have a young carer
- There is no strong evidence that young carers are more likely than their peers to come into contact with support agencies, despite government recognition that this needs to happen
- Young carers have significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers. For example, the difference between nine Bs and nine Cs
- Young carers are more likely than the national average to not be in education, employment or training (NEET) between the ages of 16 and 19

> *"It would be good to have the school more involved"*

> *"I sometimes get to do my homework in my breaks or lunchtime but then I don't get a break to see my friends. If I don't get my homework done on time I get a detention"*

> *"Coming to club helps me to talk about things that worry me and I trust the people here"*

> *"I wish I didn't have to do this because my friends invite me over but I have to say no. I can't have friends over because it stresses mum out and she does not want to upset me by saying no"*

Parent carers

The council's Herefordshire Children and Young People's Plan 2015 - 2018 aims to support children and young people's families by:

- Enhancing local support for families, including family-based respite services, retaining existing budgets and reinvesting our resources
- Developing personal budgets and personal health budgets to enable families to exercise more choice and control over their lives
- Developing clear advice, signposting and information to enable children, young people and their families to make informed choices and take control
- Collaborating with parent carer groups and forums in shaping support that enables families to participate in education, training, leisure and employment opportunities

Parent carers in Herefordshire said that:

- Getting a diagnosis is difficult and other services are dependent upon it. Once there is a diagnosis, more opportunities open up
- Schools don't always understand behavioural complexities which come with some disabilities

> *"As my son was disabled from birth, initially I was mum of a young child but eventually realised that this will go on forever and I was both mum and carer"*

> *"There is not a lot of information available through the school because it is a mainstream school. A lot of contact I have had with them has involved explaining again and again and again why he behaves the way he does. It is particularly frustrating because it's all written down, yet when he goes into a new year group, we go through the same thing – they don't seem to read the records"*

> *"Our son was born with Down's Syndrome so I always knew he would need more support, I just didn't realise how much until he was 3 - 4 and still unable to do the things my other two children could"*

There are also approximately 8,620 children and young people who require support with their mental health or emotional resilience. The Herefordshire Children and Young People Mental Health and Emotional Wellbeing Transformation Plan 2015 – 2020 aims to improve how families of young people with mental health issues are identified and supported to access help in a timely manner.

A recent report by Carers UK, 'Missing out: The identification challenge', said:

Those caring for a disabled or seriously ill child took longest to identify themselves as carers. They were much less likely than average to identify themselves immediately as a carer and significantly more likely to take longer to identify their role.

More than one in three parent carers (37%) took longer than five years to recognise themselves as a carer.

For many parent carers, it can take a long time to get a diagnosis for their child, or can take time for the severity or characteristics of a condition to become apparent as the child grows older. The delay in identification may also be because parent carers are more likely to see themselves as simply 'mum' or 'dad' rather than as a carer.

Working carers

National research by Carers UK tells us that:

- Over 2 million people have given up work at some point to care for loved ones and 3 million have reduced working hours
- The peak age of caring also often coincides with the peak of an individual's career in their 40s to 60s
- Women aged 45 to 54 were more than twice as likely as other carers to have reduced working hours as a result of caring responsibilities
- 71% of working carers have felt lonely or isolated in the workplace as result of their caring responsibilities
- 70% of carers were over £10,000 worse off as a result of reduced earnings
- Caring can have a long-term impact on ability to work, as loss of skills, knowledge, experience and confidence makes returning to work, when caring ends, extremely challenging
- Working carers often struggle to get time off to co-ordinate care services or attend medical appointments. 34% had used their annual leave to care and 21% had been forced to use sick leave

Working carers in Herefordshire said that:

- They try to keep working and meeting the needs of the person they care for but something has to give
- Experiences vary depending on how flexible their employer is
- Skills become out of date the longer they are caring, making it difficult to get back into work
- New skills gained as carers aren't recognised as useful to potential employers
- Being self-employed is exceptionally difficult due to conflicting demands

> *"Home Start was amazing, taking my wife and daughter out, doing simple every day things while I was out working, play groups, swimming. Eventually her needs became too great and I had to take redundancy"*

> *"I was lucky to have a manager who understood my caring role. I was able to slip out to make phone calls or appointments. Had he not been so flexible, I would have seriously had to think about leaving my job and risk losing my house. The prospect terrified me"*

Older carers 65+

Older carers are people who are aged 65 years and over who carry out an unpaid caring role.

Older carers in Herefordshire said that:

- They are most likely to go to their GP as a starting point for advice, with mixed outcomes
- Their own health has a huge impact on their ability to fulfil their caring role and they have concerns about who would continue in their absence
- Poor mobility caused by their own illness or disability, combined with limited transport options, mean it is difficult to access services
- Universal services don't recognise when a carer's health is failing and no one checks if they are okay

Carers UK report that almost 1.3 million people in England and Wales, aged 65 or older, are carers.

The number of carers over the age of 65 is increasing more rapidly than the general carer population. Whilst the total number of carers has risen by 11% since 2001, the number of older carers rose by 35%.

Dementia – a growing demand

Dementia presents a significant and urgent challenge to Herefordshire. The severity of dementia increases with age and reduces an individual's ability to live independently.

- It is estimated that 3,099 people in Herefordshire are living with dementia
- The number of people with dementia is estimated to increase by 2020 to 3,575
- 56% of those with dementia are undiagnosed
- There is an increase in life expectancy of people with learning disabilities, who are more likely than the general population to develop early onset dementia. One in three people with Down's Syndrome develop dementia between the age of 50 and 59

Carers and other family members of people with dementia are often older and frail themselves, with high levels of depression, physical illness and a diminished quality of life. Getting the right care, at the right time, could enable someone to remain in control of their care for longer, including optimising the time they can live at home.

> *"When I was ill and admitted to hospital, I couldn't speak and no one seemed to know or understand my wife was at home on her own and needed looking after. This made me very anxious about what was going on at home and slowed my recovery as a result"*

> *"Consultants at the hospital do not listen to carers or recognise their caring role"*

> *"If I take the medication prescribed, I cannot look after my wife because it sedates me"*

Former carers

Carers often report becoming isolated as a result of their caring responsibilities. This is often attributed to a lack of understanding from others about their caring role. In addition, leaving paid work and being unable to take time off from caring can result in losing touch with friends, colleagues and family members. When the person being cared for moves on or passes away, alongside the grieving process there can be an added likelihood of increased isolation, as the carer also loses the interaction they had with support and care providers.

The 2014 Carers UK 'State of Caring report', noted that 57% of respondents said they had lost touch with friends and almost half attributed this to a lack of practical support to enable them to socialise.

Former carers have said that:

- No one checks up on them after their loved one moves on or passes away
- There is a huge sense of loss and no sense of purpose or direction
- Where the person cared for has moved on, the carer still has a role within their ongoing care. It is important that the new care provider uses the carer's wealth of knowledge to adopt a team approach
- They have built up skills which could be used for a new career, but they don't know where to start

> *"No one checked I was okay after my wife died. I didn't expect anyone to, but it would have been nice. I wasn't okay and it took a long time to sort myself out"*

Specific condition carers

A specific condition carer provides care to an individual with complex needs. This might be one condition which is complex in nature or a number of illnesses or disabilities which make their needs complex. For example: mental health illness, alzheimers, autism or a learning disability.

Information is usually provided by national organisations specifically aimed at the needs or diagnosis of the cared for person. Within this, often advocacy or advice for the carer is also offered.

In Herefordshire, there are a number of groups which have been set up locally by organisations or individuals to provide networking and mutual support. These groups can be found on Herefordshire's WISH website at www.WISHerefordshire.org

Specific condition carers in Herefordshire said that:

- Leaflets are given out by GPs when the cared for person is diagnosed, but there is nothing for the carer
- The carer has to do their own research to find what help is out there. Services aren't offered, they are sought
- Services are denied unless the carer fights for them
- The carer's concerns about the person they care for are not heard
- The impact upon the carer relating to decisions made about the person they care for is not considered. For example, a cared for person was placed in a hospital three hours away. The carer had to travel this distance three times a week which impacted on their own health
- GPs and mental health services do not understand each other's thresholds or the impact on the carer of being passed around
- National organisations are generally more helpful and understanding
- Generic services are offered when more specific services are appropriate

> *"ABC (eating disorders organisation) was a lifeline. They told me the pathway and gave me the tools to fight to get what we needed"*

> *"No one understood my wife like I did. I tried to tell her nurse what her conditions were and it was clear she had never heard of them. It didn't give me any confidence in what would happen if I wasn't around. It makes me anxious and ill"*

Part four - Context

4.1 The national picture

The 2015 Carers UK 'Facts about Carers briefing', estimates that we will see a 40% rise in the number of carers needed by 2037. This is an extra 2.6 million carers, meaning that the carer population in the UK will reach 9 million.

They note, importantly, that:

Carers are not a static population. Each year millions of people take on caring responsibilities, whilst caring comes to an end for millions of carers as the person they care for recovers, moves to residential care or passes away.

This turnover means that caring will touch the lives of most of the population, as we all need or provide care or support family members caring for loved ones at some point in our lives

4.2 The local picture

Herefordshire is a predominantly rural county. The current (mid-2013) estimate of the county's resident population is 186,100, an increase of 1,200 people since mid-2012.

- Over half of all residents live in areas classified as rural, with two in five (78,900) living in the most rural villages and dispersed areas
- Herefordshire has an older age structure than England and Wales, with people aged 65 and over constituting 23% of the county's population (42,000), in comparison with 17% nationally
- By 2031, projections suggest that 30% of Herefordshire's population will be aged 65 and over, compared to 23% nationally
- The latest census figures indicate that there are 20,627 adult carers in Herefordshire. However, the Herefordshire Health and Wellbeing survey in 2011 estimated that there were 34,200 and this number will have risen since that date. It is anticipated that there are additional carers who do not identify themselves as such, but are carrying out their caring role supported by informal networks of friends and relatives or are self-sufficient
- In 2014/15, 1,428 people in Herefordshire had a diagnosis of dementia (GP Quality Outcomes Framework data - March 2015). By 2030, it is projected that Herefordshire will have around 5,000 people aged 65 and over with dementia, which is almost four times as many individuals

In summary, the rural nature and age profile of Herefordshire residents presents unique challenges in service design and delivery. This affects both those requiring support and care and their carers.

4.3 The legislation

The Carers Strategy supports Herefordshire Council and Herefordshire Clinical Commissioning Group, along with health and care delivery partners, to meet their legal duties and deliver the prevention and wellbeing principles which underpin the Care Act 2014.

The range of legislation and guidance relating to carers can be found in appendix A (page 43). The most significant of these, from the perspective of supporting carers, are the Care Act 2014 and the Children and Families Act 2014.

The Care Act gives carers the same rights to assessment and support as the people they care for. It includes duties for local councils to:

- Consider the wellbeing of people in all actions undertaken, including carers
- Provide relevant information and advice so that people (including carers) can receive information regarding how to look after themselves, as well as the support and care available from adult social care services
- Put services in place that prevent, reduce or delay people needing services
- Assess the impact of caring on the carer and what needs to happen to ensure they can continue in their caring role. Carers who are eligible will be entitled to have their support and care needs met. For those who are not eligible for assistance under a formal assessment, information and signposting will be provided

The Care Act includes a duty to undertake a transition assessment for:

- Parent carers when the young person they care for is approaching 18. This means the local council can commence services following an assessment prior to the young person reaching transition
- Young carers to understand the changing demands on them as a carer as they transition into adulthood

The Children and Families Act and Care Act introduce additional responsibilities in respect of young carers. Both Acts highlight the need for local councils to take a whole family approach to identifying and assessing young carers and the need for a joint adult and children's services approach to carrying out assessments.

The Children and Families Act also strengthens the rights of parent carers. Their wellbeing must be addressed, including whether they wish to work, undertake education, training or leisure activities.

The Adults Wellbeing Plan for 2017 - 2020 expresses the priorities set out in the Health and Wellbeing Strategy and the council's vision that:

"Herefordshire residents are resilient, lead fulfilling lives, are emotionally and physically healthy and feel safe and secure."

The Health and Wellbeing Strategy details that in order to achieve the vision, the council needs to:

- Keep people well (prevention)
- Get people better
- Help people cope

Associated with the strategy, the vision for Herefordshire Council's adults and wellbeing directorate is that:

"All adults in Herefordshire live healthy, happy and independent lives within their local communities, for as long as possible, with support when they need it."

The council recognises that supporting carers to keep well and continue in their caring role will help adults, both the cared for person and carer, to live independently for longer.

The Children and Young People's Plan 2015 - 2018 set out the council's vision:

"We want all children and young people in Herefordshire to have the best start in life and grow up healthy, happy and safe within supportive family environments.

We want them to have the best possible health, education and opportunities."

In order to deliver this, the council stated it would:

"Work with individuals, families and communities to develop capability and resilience."

This includes identifying parent carers, young carers and young adult carers, assessing the whole family based on its strengths and building upon this with access to information, advice and services as appropriate.

4.4 The resources

The value of our unpaid carers to those they care for and Herefordshire's communities is far greater than the money their efforts save the state.

It is clear that demand for services within the county will continue to grow and that national funding will not be increased to meet this. Universal services and partners need to join thinking and work smarter in terms of delivering services which address the priorities and key issues facing carers.

Herefordshire Council's Medium Term Financial Strategy identifies that between 2010 and 2020, savings of £87 million are required to maintain a balanced budget. It expects to have achieved £69.5 million by the end of 2016/17, leaving a further £17.5 million to be delivered within the following three years.

At the same time, the Herefordshire and Worcestershire Sustainability and Transformation Partnership (STP) Plan identifies a funding gap of £86.5 million across the Clinical Commissioning Groups and NHS providers (principally Wye Valley NHS Trust) by 2020/21, arising from demographic pressures, inflation and other factors, if it does not act to address the financial pressures.

Nevertheless, Herefordshire Council will retain funding for the purpose of commissioning support for carers, as will Herefordshire Clinical Commissioning Group (CCG). These resources will be used to fund reconfigured contracts for carers' services from April 2018. In addition, the council and CCG will continue to commission and fund respite services for adults and children and, in many cases, these also provide direct benefits to carers.

It is clear that beyond these resources, the NHS, in particular, indirectly spends a significant amount on carers in a variety of ways. Work is continuing to identify and quantify these existing and often unseen resources, as a part of the health and care economy.

Between 1 April 2016 and 3 March 2017, Herefordshire Council provided short breaks for 160 children. For adults over the same period, 106 people received replacement care through nursing placements and 244 people through residential placements.

Appendix A
Plans, acts, data sources and strategies

The Care Act 2014

The Children and Families Act 2014

GP Quality Outcomes Framework data - March 2015

Herefordshire and Worcestershire Sustainability and Transformation Partnership (STP) Plan

Herefordshire Council's Adults Wellbeing Plan for 2017 - 2020

Herefordshire Council's Children and Young People's Plan 2015 - 2018

Herefordshire Council's Corporate Plan

Herefordshire Clinical Commissioning Group's Five Year Strategic Plan

Herefordshire Council's Health and Wellbeing Strategy

Herefordshire Council and NHS Herefordshire's Herefordshire Health and Wellbeing survey

Herefordshire Council's Medium Term Financial Strategy

Herefordshire Clinical Commissioning Group's Herefordshire Children and Young People Mental Health and Emotional Wellbeing Transformation Plan 2015 – 2020

Appendix B

References

2013 The Children's Society 'Hidden from view: The experiences of young carers in England'.

2014 Carers UK 'State of Caring report'

2015 Carers UK 'State of Caring report'

2015 Carers UK 'Alone and Caring report'

2015 Carers UK 'Facts about Carers briefing'

2015 Carers UK 'Missing out: The identification challenge'

2015 Carers UK and the University of Sheffield 'Valuing Carers 2015: The rising value of carer's support'