



April 2017

Support for carers

Exploring support requirements for carers in response to engagement carried out in 2016



**Happy
Healthy
atHome**

NHS

**North East Hampshire and Farnham
Clinical Commissioning Group**



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Introduction

Healthwatch is the independent consumer champion for health and social care in England. Healthwatch's function is to engage with local people to seek views about locally delivered services, signpost service users to relevant information and to influence the design of local health and social care provision.

Healthwatch Hampshire is part of a network of local Healthwatch across 148 local authority areas that launched in April 2013 to ensure local voices are heard and enable them to influence the delivery and design of local services. Our sole purpose is to understand the needs, experiences and concerns of people who use health and social care and to speak out on their behalf. Healthwatch have statutory powers, as stated in the Health and Social Care Act 2012, to ensure the consumer's voice is strengthened and heard by those who commission, deliver and regulate health and care services. Local Healthwatch helps people get the best out of their local health and social care services; whether it's improving them today or helping to shape them for tomorrow.



The CCG Vanguard Programme, 'Happy, Healthy, at Home', is aspiring to drive a culture change across the system and put engagement and co-production at the centre of everything they do. This means that local people need to be actively participating in the design and delivery of services.



In 2016 Healthwatch, along with the North East Hampshire & Farnham CCG Vanguard Programme 'Happy, Healthy, at Home', developed a project around support requirements for carers in North East Hampshire and Farnham. The conclusions from this project, which involved engaging with a variety of carers groups across North East Hampshire, found that there were four main topics that carers highlighted as being the areas in which they most need support.

- **Peer support**
- **Respite support**
- **Information and advice**
- **Health and Wellbeing**



Background

Healthwatch Hampshire have created this report to assist directly in the commissioning decisions being made as part of the vanguard programme in relation to support services for carers in North East Hampshire and Farnham.

There were many recurring themes relating to the need for more respite, financial and emotional support, while bearing in mind the practical implications of caring that need addressing too.

The support that carers need depends on the person they are caring for, the carers work, education and/or family commitments. Alongside this their own needs, their age, the amount of care they are providing, the type of condition there are caring for and the carers physical and emotional wellbeing all play a part. That is why it is essential that support services where possible are tailored to meet individuals' needs and that there is easy access to information on local networks of support.

Between January and March 2017 Healthwatch revisited the groups from the first phase of the project, to get their opinions on how support covering the four topics should be delivered. We also wanted to share with the groups that the CCG had taken notice of first phase of the project and wanted to look at developing services using their feedback.

Alongside face-to-face engagement with previous participants, Healthwatch Hampshire designed a survey that could

be completed on-line or on paper to ensure that as much feedback as possible was gained, in ways that were accessible and useable by carers from diverse backgrounds and in different situations. We promoted the surveys through our partners, and visiting groups enabled us to gain as much feedback as possible using several different engagement techniques. Using the surveys also helped us to develop a wider picture across Hampshire of what is needed by carers. The survey was sent out to all partners/agencies who come in contact with carers to promote the project and get as much feedback as possible, but with a focus on North East Hampshire to ensure that the majority of feedback was from the area the services were being developed for. All the groups visited were from the north east Hampshire area.

The project has been well received and we have 198 surveys completed, and Healthwatch have spoken to over 30 people from the engagement events in the North East Hampshire. We are pleased with this response and believe that we can build a realistic picture of how service users want support services delivered for carers in North East Hampshire.

A full copy of the 2016 'Support for Carers' Report can be found here:

http://www.healthwatchhampshire.co.uk/sites/default/files/support_for_carers_-_june_2016_final_report.pdf



Demographics

The vast majority of carers reported that they were looking after a family member (92%) and 38% of these are working either full or part time with 47% being retired or not working. 72% of survey participants are of working age, broken down between two brackets 25-49 years old and 50-64 years of age, 22% were aged between 65-79 and only 3% over 80 years old. This gives a clear picture of the diversity of carers in the region, and highlights the different pressures and responsibilities that carers are dealing with along with their caring responsibilities.

20% of those surveyed considered themselves to have a disability, emphasizing the need for carers to have access and support that meets their needs along with the person they are caring for.

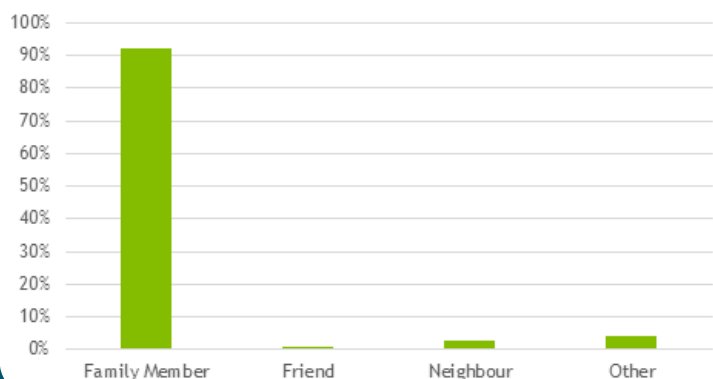
The majority of carers we spoke to described themselves as full time carers (48%), a further 15% reported over 24 hours caring duties per week.

Also included in this project are an number of seldom heard communities within North East Hampshire and Farnham. Alongside the survey we also carried out specific targeted engagement with the Nepalese community, young Carers, carers with mental health issues and the military community. We engaged with these groups through links with partner agencies who work with and support them.

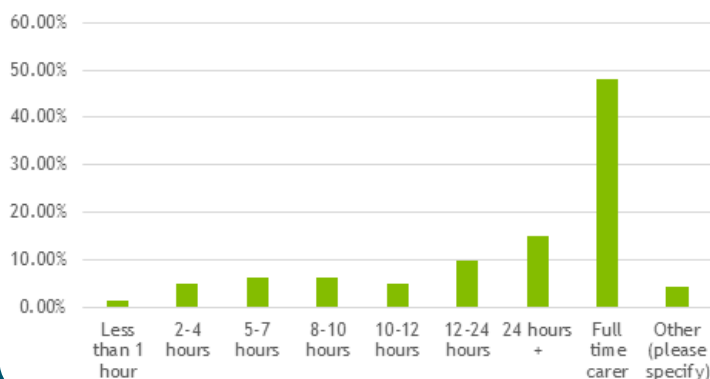
This enabled us to identified specific issues that impact on these groups accessing support for carers. Whilst we found that overall the responses, regardless of who we spoke to, were very similar, there were a number of specific issues for these communities which are highlighted throughout the report.



Who do you provide support and care for?



How many hours a week do you spend caring?





Nepali Carers

Many of the Nepalis carers have similar issues to the other groups/participants who took part in the survey such as isolation, financial concerns and the need for respite or domiciliary care. Although this is impacted by problems in communication and cultural differences that make it more difficult to access support services. None of the Nepalese community that we spoke to attended the Carers Hubs in the local area, or registered as a carer with their GP. To ensure that this community is well informed about support services it is vital to engage with them through agencies and partners who have regular contact with Nepalese community, have built up a good relationship with them, and have access to interpreters and community leaders.



Young Carers

Healthwatch Hampshire found it difficult to engage with this group face-to-face despite contacting agencies who support young carers. This was due mostly to the timescales of the project and the changes that have happened locally with the delivery of support services to young carers. The agencies we spoke to were

reluctant to allow us to run workshops with the young carers at the clubs they run as they felt it was taking up valuable ‘time out’ from their caring duties. We gained most of our information through surveys that were disseminated through the Young Carers networks. One thing that did stand out from our work with Young Carers is the need for the carers assessment to be done, staff who work with this group are reporting that many young people they support do not have the assessments done.

Quotes from young carers show the impact that caring has on their lives, and the support they require:

“When I became a carer for my Mum and my brother, I needed help to understand the role I was undertaking. I didn’t know what a young carer was, I just did it for years” Young carer, 15 years old

“I administer medication but no one has ever explained to me what it’s for, what possible side effects might be or anything” Young carer, 15 years old

“Anxiety and worrying keeps me awake at night. Everything in my life has a time limit and there isn’t enough time to get everything done. I also worry that my brother might stop breathing at any time” Young carer, 14 years old



Carers and Mental Health

Caring for someone with mental health issues

The carers we spoke to who supported someone with mental health issues told us that they felt ill equipped to deal with some of the issues that arise in this situation. They sometimes did not understand how best to deal with challenging behavior or the future implications that come from a diagnosis. They also felt that mental health had so many variants that it was too simplistic to put everyone with a mental health diagnosis under one umbrella. Young people would need different support to an older person with dementia, and would benefit from different respite activities.

Impact on mental health for carers

Many of the carers we spoke to felt that their caring responsibilities had a detrimental impact on their own mental health. Feeling isolated and responsible for the wellbeing of another can be overwhelming. The physical impact of caring for someone who may wake during the night, get confused and aggressive or have mobility issues also increased the toll on the mental health of the carer. To maintain their physical and mental health carers told us they needed to be able to access information and support easily, and be able to get respite from their caring duties knowing they had time available to look after themselves without worrying about the person they care for.

Military Carers

Military families can have very transient lives and may be moving on every 2 years, this means that on a regular basis they have to build up the contacts for support and information in a new area, and this can be time consuming and difficult. There have been cut backs to family support workers in the military and this leaves families unsupported and vulnerable. Military carers also report that when a parent is working away for long periods of time there is a shift in dynamics within the family and caring roles are taken on by other members of the family. This could be a child, and it is important that they can access support through schools, and outside agencies. One of the things highlighted by military carers is the fact that they may have caring responsibilities that they manage from a distance, being posted away from elderly parents for example. They wanted to know that they can access support easily and find the right technological support which can help them know their loved one is safe and cared for.





Supporting work

1. Care at home survey

Healthwatch Hampshire have recently completed a large scale survey regarding the experiences of people currently receiving home care services in Hampshire. This was primarily to help inform future commissioning and contracting decisions and to provide recommendations for providers of care services to ensure that services are doing everything they can to meet the needs of those in receipt of care at home.

Healthwatch worked with Hampshire County Council to distribute a bespoke survey to everyone in receipt of care at home services in Hampshire. Approximately 6000 surveys were sent out by post and an online version was also available via the Healthwatch website. The full report is available on our website but relevant findings regarding informal care have also been included in this report. Over 850 responses were collected and one of the main themes to emerge was around informal care with almost half of respondents receiving extra support from friends, family or neighbours. 70% of those that received extra support did not receive any respite care to give their carers a break. Only 2% of respondents felt that adequate respite was provided for their informal carers. A full breakdown of the information received and the recommendations made are included in Appendix One.



2. Citizen's Advice survey

During the delivery of this engagement work, our partners at Citizens Advice ran a complementary survey to support this work and offer further insight into the needs of the local community. The detailed findings have been taken in to account throughout the report but can be summarised as follows:

- 48 responses were received
- 42/48 (87.5%) of respondents cared for a family member, 4/48 (8.3%) provided care as part of their work and 2/48 (4.2%) provided care for a friend.
- 25/48 (52%) were full time carers
- 19/48 (39.6%) had a job, of which 11/48 (22.9%) were part time and 8/48 (16.7%) were full time. 14/48 (29.2%) don't currently work and 11/48 (22.9%) were retired.
- 23/48 (47.9%) were aged 50 to 64, 11/48 (22.9%) were aged 25 to 49 and 9/48 (18.8%) were aged 65 to 79.
- 10/48 (20.8%) reported they had a disability, 27/48 (56.3%) reported they didn't have a disability and 11/48 (22.9%) declined to comment.
- The most popular way to access information or advice was one-to-one, followed by online via a website, telephone advice, group sessions then social media.
- Clients identify a range of things which would benefit their wellbeing as a carer including respite care, access to information and advice and support when they need it.



Project feedback

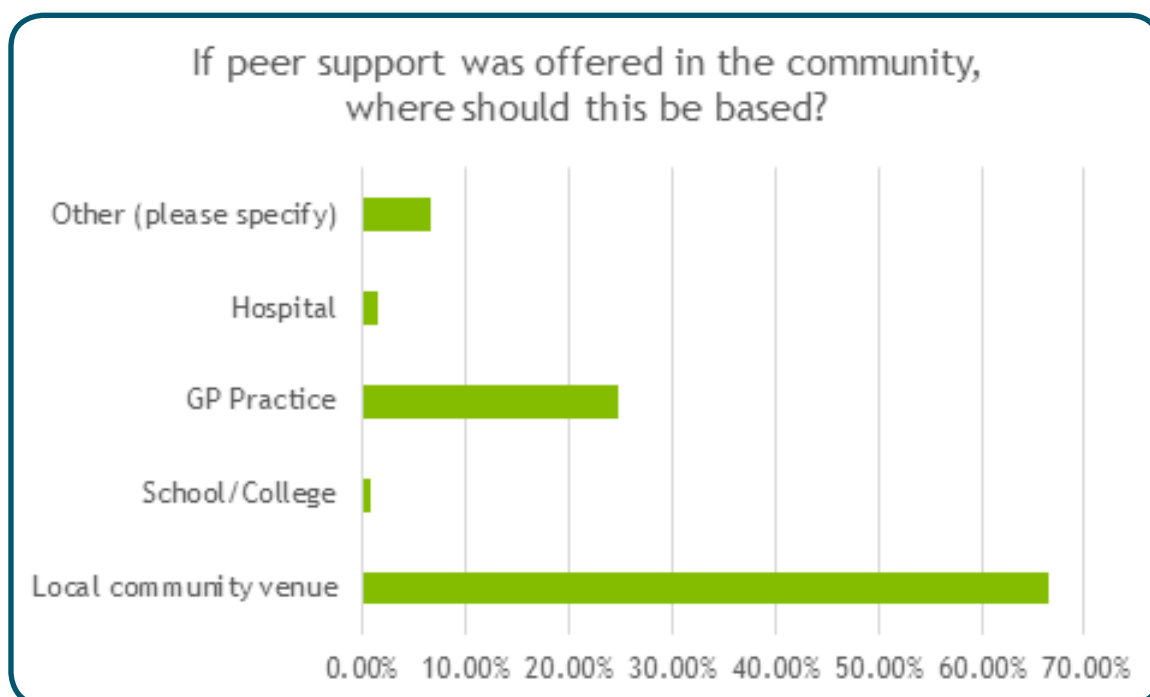
1. Peer support

The project identified that 1-2-1 support from peers was seen as most needed by carers, with telephone, groups and on-line support from websites, chat-rooms, Facebook etc being ranked of nearly equal importance.

In depth responses to the question show that people are looking for a variety of venues for this support. Carers looking after someone with a high level of needs require support in the home, while others would like support in community, local venues or GP practices. If support was to be offered in the community, the majority of carers reported that this should be in a local community venue rather than a GP surgery, hospital or school.

Carers from a Military background said they found it hard to find the right support for them locally, only staying in an area for a short time means they are have to go through the process of finding new support on a regular basis, they would like to be able identify support in a new area quickly through a one stop or up to date directory. Military families may also have the responsibility of caring at a distance for parents, relying on modern technology and would benefit from having contact with other in the same situation.

“As there are a lot of military families in the area who move frequently it would be good to have a dedicated military link for new families coming in so that they would have a point of contact for help in the area” Full-time carer, Church Crookham





Carers living in rural areas, have said they cannot always get to groups because of transport issues or the person they care for finding travelling on public transport difficult. They have said they rely heavily on what's available locally and would like support for the local community to maintain Neighbourcare schemes, and coffee mornings etc.

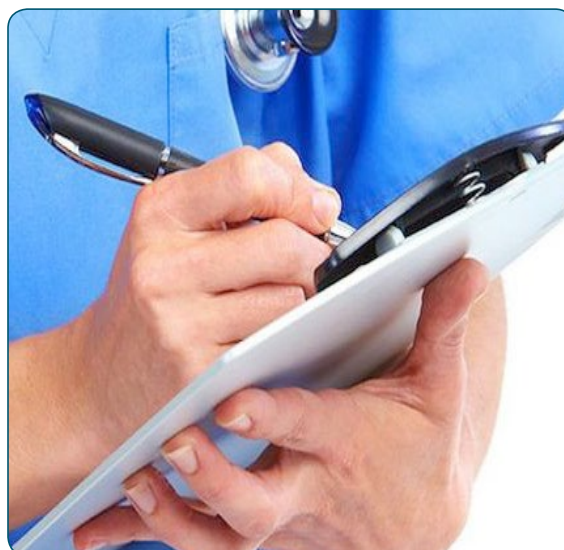
“ I do not feel that carers need yet another peer support service. what carers need is for statutory services to respond promptly, respectfully and effectively when the person they care for needs help. Statutory services still don't listen properly to carers and service users. Instead there is a small (and unrepresentative) group of carers and service users who the services offer preferential treatment to and allow to speak on behalf of all (because these people say the things that fit in with the services' agendas.) Commissioners and statutory services need to work harder to get the views of the majority of carers - who are not usually heard - and need to engage better with third sector services (who are better at hearing and representing carers' views.)” Carer, Farnborough

Carers needs differ greatly and many have found that they cannot find a group to suit their situation easily. Some carers who took part in the project said they didn't feel comfortable talking in a group and found listening to people moaning not helpful. Although others found group meeting of great value, this goes to prove the diversity of carers and their needs and wants. All carers surveyed agreed on that support for

groups was needed but alternatives should be available.

“Groups need to be for carers of people with similar disabilities so they can fully appreciate what each other are dealing with, and share tips and strategies. As different disabilities require different care, this is important. For example, my son is profoundly physically disabled. Therefore in the past I have found I have little in common care wise with those caring for (for example) learning or behavioural disabilities” Full time carer, Camberley

Carers also feel that GPs and practice staff ignore their needs, sometimes due to time constraints, but they would like the connection between their own health and wellbeing and the health of the person they care for to be recognized and supported. GPs perhaps cannot be expected to know of all groups/services available to meet so many different needs of the individual carer, but would benefit from being able to signpost to a one-stop-shop with up to date information on different types of support and services available.





Technology - Apps and technology are also needed by some carers, especially younger people who may be at work or studying. They are not always able to attend meetings, or groups but would like regular contact with others in the same situations.

Organisation - Participants felt that leaving the organisation and promotion of groups to individuals or charities made it difficult to engage with services, groups or services will end or change and it is difficult to find up to date information. It can be a bit of a lottery and rely on the carers finding the right information for them, when they are already overwhelmed by their responsibilities.

Buddy Systems - This was seen as something that could support all carers, being able to talk to someone in the same situation as them. It was thought to be best operated on a flexible systems but would need to match people in the right way.



Project feedback

2. Respite support

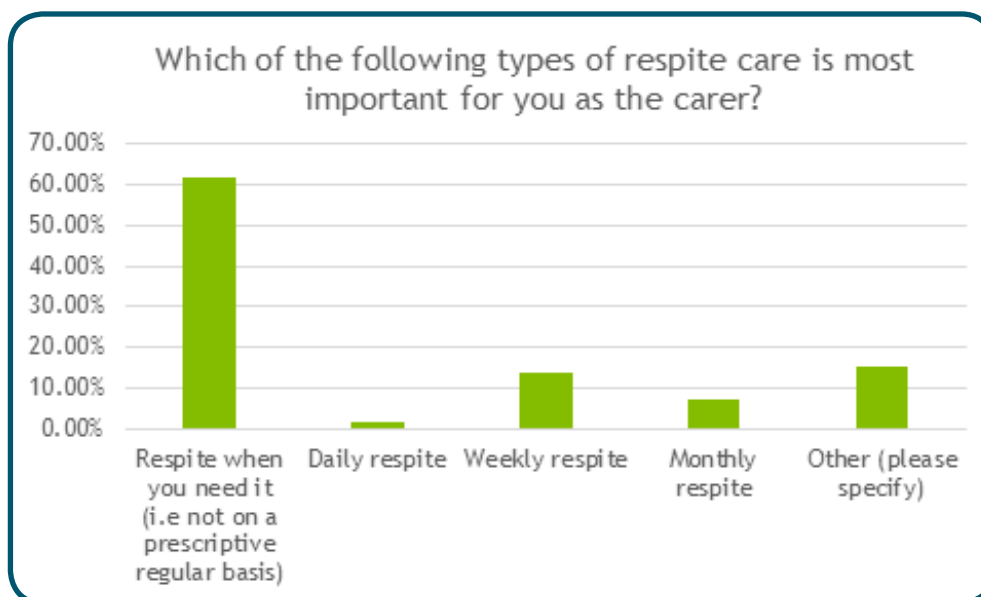
Many of the people surveyed did not know what respite was, and had never been offered or thought about how they could benefit from respite. Although some carers were concerned about leaving the people they care for with someone else, they recognised the benefit to themselves. They also felt it would need to be regular and with the same people so that the person they care for would be comfortable and they would be reassured they were happy and ok.

“Unsure as never had a holiday or proper respite...just maybe an hour or 2 out the house (& that’s mainly for my own appointments)” Full time carer, Gosport

Most surveyed would like short breaks on a monthly/weekly/regular basis, although others felt they was a benefit to having longer breaks so they could recharge over a week or few days. They was also a need for overnight care being available so that carers could get a good sleep which would benefit their health and wellbeing. There was clear message that respite is something that is not necessarily needed on a regular basis but needs to be available in a flexible way that meets flexible and ever changing need.

“One size doesn’t fit all, it needs to be flexible for each individual needs and well being” Working age carer, Basingstoke

Home or Away? - Again this is dependent very much on the needs of the person being cared for. Participants from mental



health support groups said the people they care for needed activities in a safe environment that gave them an interest, independence and a change to socialise. This also meant that the carer was able to have time to themselves, however there were also concerns that carers could be on a very low budget and not be able to access the gym or other workshops without discounted support from the local council. Other carers supporting people with dementia would like to have a familiar face that can come to their home a sit with the person needing support, while the carer can attend appointments or just go shopping on their own.

“Have people available to take some of the care duties from me. In the past a telephone service was available to deal with my brother’s problems but now he has to go to talk to people face to face. As he has severe agoraphobia this doesn’t happen” Carer for brother, Aldershot

Where to find Respite - Most carers did not know where to find respite, or how to find it. It was felt that there was need for respite to be prescribed, or advice on where to go to get respite should come from one source, GP or through carers assessment.

Respite Providers - Adult Services need to fulfill their obligation for caring out carers assessments, one individual had been waiting 18 months. There was a feeling that Adult Services were not providing support for carers or recognising that they have an obligation to make sure carers have assessments and support needs identified. Disability Challengers and Recovery College were seen as providing a great service by participants, they liked the flexibility and wanted the services to continue to receive funding to maintain services.

“There may well be some respite support or maybe not. How do I find out? A list of people, organisations or contacts is



badly needed so I know where to turn. Should there not be a person or agency in each community who has contact or a list of what is available? There might be help available but I don't know about it”
80 year old carer, Fleet

Crisis - Many carers were concerned about what to do if they need respite at short notice due to illness or unforeseen circumstances. They did not feel that they have a plan of action and rely on the good will of friends or family or just soldier on.

Cross Border Issues - Those living on the Hampshire Surrey borders found it difficult to manage services, and find out what they can access.



Project feedback

3. Information and advice

Nearly all of those who took part in the survey said they wanted to be able to access information and advice locally at community venues or in GP practices, although when digging deeper into the feedback there is a need for flexibility on this to provide access to information advice for those carers who work or young carers. A high proportion of those surveyed would like financial and legal advice and also more support around specific health issues and where to go to for help. The division between how information and advice is delivered is pretty equal, and seems to depend on the individual carer. Some carers felt they benefitted from 1-2-1 support when others are happy to get information on-line or over the phone.

“It needs to be local and specific, often the advice is too general or you just get referred to yet another service who may be able to help you. one place that can help with all the info needed locally in terms of social care support, respite and health. finance can be more generalised or be from another service.” Full time carer, under 50 years old, Yateley





Transport - Without transport getting to groups or services is an issue. There is information available through Hampshire County Council, but a local directory is needed.

One-stop-shop - Many carers participating would like a one-stop-shop systems that provides up to date information, advice and sign posting at an early stage. Somewhere carers can go back to for advice if things change, without the need to call lots of different departments and be passed backward and forwards. They would also like to have contact with an agency that knows their story, so it is personalized to suit the situation.

Online and Social Media - An accessible portal with up to date information would benefit those who are working or prefer to use this type of contact. Whatsapp groups or similar have been suggested as a form of support group, that has easy flexible access.

Problem with a lot of groups or drop in places is that they are in the day time which is hard if you work - Carer working full-time, Farnborough

Children - Parents who have a caring responsibility for a disabled child would like information on financial support and education advice. One comment was that services should be merged so that statutory information could be accessed under the Children's and Families Act.

Where? - Many carers sited local venues and GP practices to be the most suitable place to access information, but there was also a need for venues to be open outside office hours.

"You need to be signposted to support that actually exists. We've been given mountains of information over the years and none of it's any use because there isn't actually a service provided anyway." Full-time carer, aged under 50 years old.



Local specific - One place to provide all information on social care, respite, health and finance to avoid the need to call lots of different departments and being re-directed. Signposting to support that exists and is relevant to the individual's needs. A holistic and joined up service to provide up to date relevant information.

1-2-1 - Many carers felt they would benefit from 1-2-1 support either in the home or face-to-face, some said they would like someone to check in on them at regular intervals to make sure everything was ok.



Project feedback

4. Health and wellbeing

When questioned about training for carers, 83% said they had not received any training to support their caring role or their health and well-being. 61% would like training on how to cope with emergencies and 71% would like emotional or counselling support. Regular health checks for carers and support for their caring role were also identified as an area of high need.

Carers health - Carers felt that it was vital that their own health and wellbeing was looked after in order for them to provide the right support for the person they cared for. They recognised that there was an emotional toll on their health and wellbeing as demonstrated by the graphs overleaf.

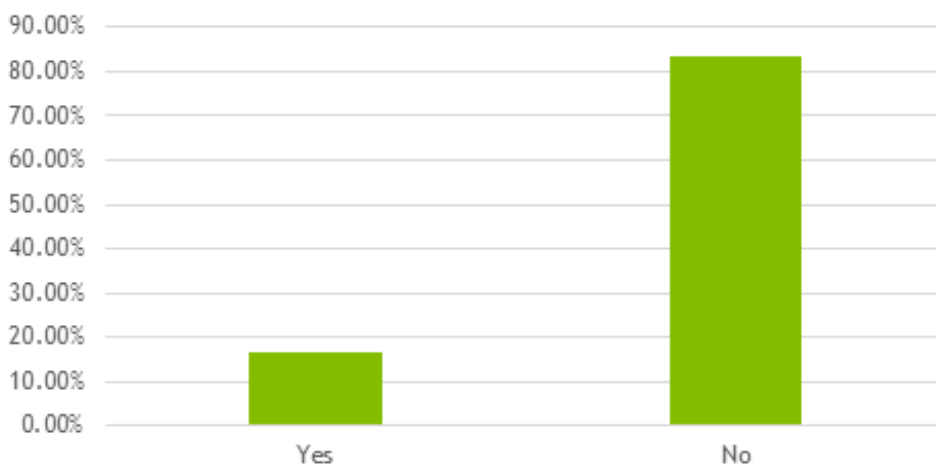
“Training in dealing with a person with severe mental health issues, who does not always think logically and who sometimes obsesses about problems which most people would dismiss as minor.” Carer, Aldershot

“Training and reassurance on catheter care” - Full-time carer,

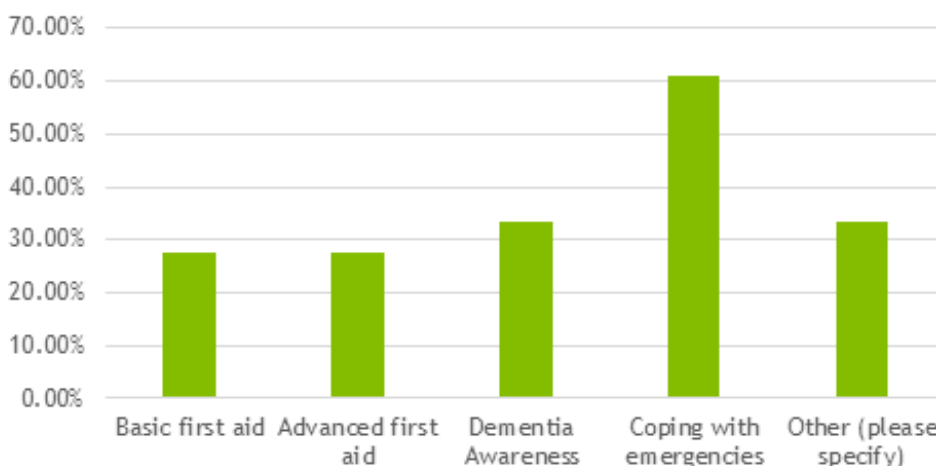
“Moving and handling. Health and safety. My son has severe epilepsy but I've never had basic first aid or seizure training! Its absurd!” Parent carer, sharing caring responsibilities with husband, Camberley



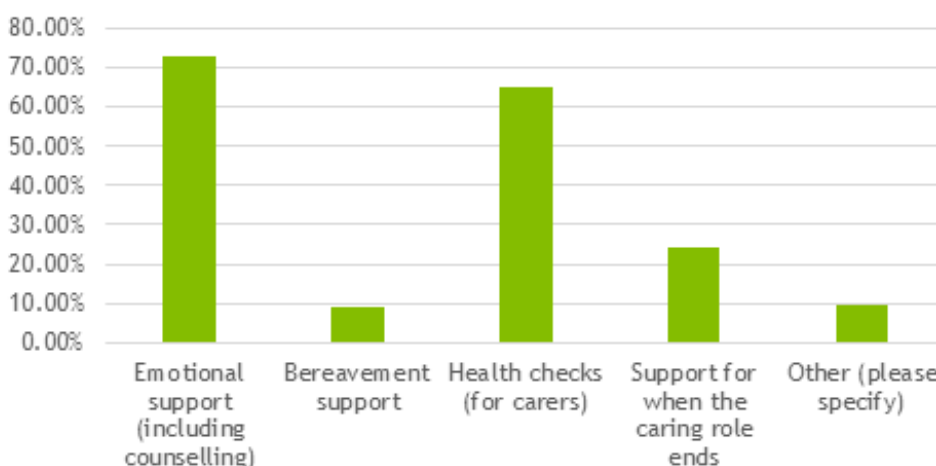
Have you ever accessed or received any training to help you carry out your support/caring role?



Which of the following training would you find useful in your current situation?



Which of the following services would be useful to you in your current situation?





Summary



Healthwatch Hampshire have created this report to assist directly in the commissioning decisions being made as part of the vanguard programme in relation to support services for carers in North East Hampshire and Farnham.

This report highlights the diverse needs of carers depending on variants in age, circumstances, location and the specific condition/needs of the person that are caring for. It has identified the need for a flexible and adaptable approach to support services for carers, combining the need for face to face support from professionals and groups, and the more indirect approach of having portals, and hubs that can provide information and support at a distance and more flexibly.

Carers have said how the lack of respite impacts on their emotional and physical health, and how important it is to maintain this in order to continue to provide care. The isolation of being a carer is not only addressed by peer support but by having access to regular respite that enables carers to have time out from their caring duties, to re-charge their batteries. Carers would also like support from local councils to provide discounts or funding for leisure activities that can adapt to the individual carers circumstances.

Having access to up to date relevant information and advice needs to be easy to access. Carers feel they already have enough pressure on them and having to contact lots of different organisations or departments adds to that. Although different carers require this information in different formats, all agreed they would like to access information and support from one point of contact.

“One thing that would help... Being able to access a ‘one-stop’ shop for information on the services available in the area and support groups.”

Full-time carer, Church Crookham



Recommendations

One-Stop-Shop for carers

One point of contact to be able to access support/advice/signpost.

Most carers whatever their circumstance would like to have one point of contact for support. This also needs to be accessible in a variety of forms, telephone, email, website, social media. Our research shows that access to support and information can vary greatly across North East Hampshire & Farnham, and should not depend on individual staff/professional knowledge and information sharing in the area. The survey also highlighted the issue around information being up to date.

Recognise the diversity of carers needs

Carers all have different experiences and needs, one size does not fit all.

All carers have different circumstance and needs, this should be reflected in the support services provided. A carer that works full-time or a young carer would not visit a Carer's Hub, partly due to them being at school or work, but also they would not feel that they can identify with this group. Resources need to be directed in a flexible and adaptable way to encompass the wide variety of circumstances carers find them self in.

Provide appropriate training

Many carers have very little training for the role they are undertaking, and can feel vulnerable and overwhelmed.

The need for training in First Aid, Lifting and Handling and other medical care procedures along with support for carers to maintain their own health and well-being in evident from the survey. Some of the groups we spoke to were very complimentary and supportive of the Recovery College running in NE Hants and Farnham, and the courses they provide. It was felt this format was beneficial to carers and those who they cared for in providing support.

Consider realistic and appropriate provision of respite

Needs to match the individual's needs

There is a definite need for respite identified in the survey, and again, this needs to be flexible. Some carers would like support to access groups for the person they care for, while being able to have 'time out' for themselves. Many carers talked about the benefits of being able to access discounted transport, leisure centres,



and other social venues through a card or system run by the local council. There are still some carers who would like to be able to access respite that means they can leave the person they care for in a safe, comfortable environment and have a few days away from their caring duties.

Consider a different approach for seldom heard carers

Deliver information in the most appropriate and effective way

Seldom heard carers (including young carers, the napli community, the military community and those effected by mental health issues) are best served through building good relationships with the agencies that support them. They are less likely to identify themselves as carers and seek help through the usual roots. The agencies who work closely with these groups need access to up to date information that they can disseminate to the service users. Staff working with young carers expressed their concern that Carers Assessments are not be carried out with young people who had caring responsibilities and they were not getting the support they are entitled to from Social Services.

Improve information and signposting services

This needs to be up to date and easily accessible

Many carers felt they were getting information that was out of date, or having to go through lots of different sources to get the information they need. This can be time consuming and demoralising, many of them said they gave up after making lots of phone calls or trying to access support that was no longer available.

More widespread advertising of carers assessments

Ensure that informal carers get the support they are entitled to including information, advice, emotional health and wellbeing support and respite care

This report highlights the ongoing need for further support for informal carers. We recommend more widespread advertising of carers assessments, by the CCG, Hampshire County Council and throughout the voluntary sector network to ensure that informal carers get the support they are entitled to including information, advice, emotional health and wellbeing support and respite care.



What next?

Over 250 carers from North East Hampshire and Farnham shared their experiences, ideas and recommendations about how support services for carers could be improved in the future. There were many recurring themes relating to the need for more respite and more financial support, as well as practical ways that health and social care professionals could help to reduce stress for carers. All of the groups also strongly emphasised the need for more emotional support but said that this emotional support could only be accessed and beneficial if the practical implications of caring are addressed too.

The support that carers need depends on the person they are caring for, the carers work, education and/or family commitments, their own health needs, their age, the amount of care that they are providing, the type of condition that they caring for and the carers emotional wellbeing. That is why it is essential that support services, where possible are tailored to meet the individuals' needs and that carers and health and social care professionals are well-informed about the local network of support and the support that is offered is inclusive to all.

Healthwatch Hampshire were commissioned by North East Hampshire and Farnham CCG to carry out this work. Healthwatch are ultimately accountable to local people and prioritise the work we do to reflect the intelligence and evidence we have gathered from local people. Our independence from the NHS and local authorities mean that we are not bound to adopt the priorities or messages of those bodies. We always encourage commissioners and providers to carry out their own consultation and engagement to support their decision making processes.

All responses and feedback will be published alongside this report on our website: www.healthwatchhampshire.co.uk





Contacts and useful links

For information about care and support available for adults in Hampshire visit:

www.hants.gov.uk/gettingstartedguide

For information about receiving support as a carer visit:

www.hants.gov.uk/carers.htm

The following charities and third sector organisations also provide further support and information:

Carers Trust - www.carers.org.uk

Carers UK - www.carersuk.org

Princess Royal Trust for Carers - www.carers.org/partner/princess-royal-trust-carers-hampshire

Age Concern - www.ageconcernhampshire.org.uk

Alzheimer's Society - www.alzheimers.org.uk

Mind - www.mind.org.uk

Alzheimer Cafe UK - www.alzheimercafe.co.uk

Citizens Advice Hampshire - www.citahants.org

To download a copy of this report or to share feedback and experiences about health and social care services in Hampshire get in touch with us at Healthwatch Hampshire:

www.healthwatchhampshire.co.uk

01962 400262

In person at any Citizens Advice Bureau





Appendix One

The following is an extract from our full ‘Care at Home’ report available on the Healthwatch Hampshire website.

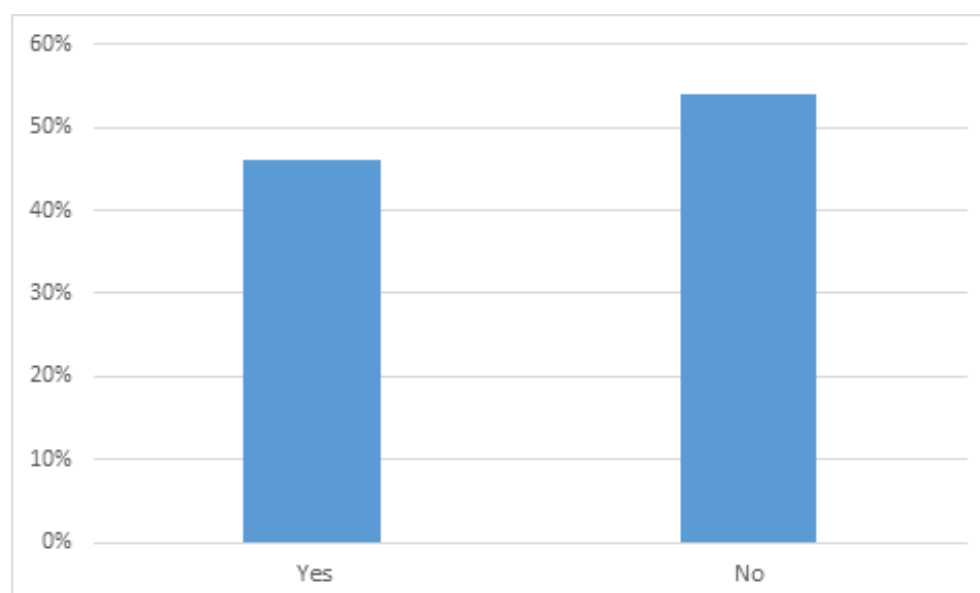
‘This needs to be looked at and not ignored’ Support for informal carers

“Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid” Carers UK

There are over 100,000 people in Hampshire providing unpaid informal care in Hampshire (Carers Together). Although the focus of this project is home care services and care that is provided by professionals, Healthwatch Hampshire felt it important to understand what level of support people receive outside of their funded care. The hope is that this provides useful contextual information to understand the levels of support people require.

Almost half of all respondents reported that they received practical help from friends, family or neighbours alongside their paid for care.

Do you receive any practical help (for example, dressing or showering) from friends, neighbours or family members? 853 responses



Hampshire County Council provide carers assessments for informal carers who feel they may also need extra support or ‘respite’ care to cover them while they have a break from caring responsibilities. The aim of a carer’s assessment is to find out about

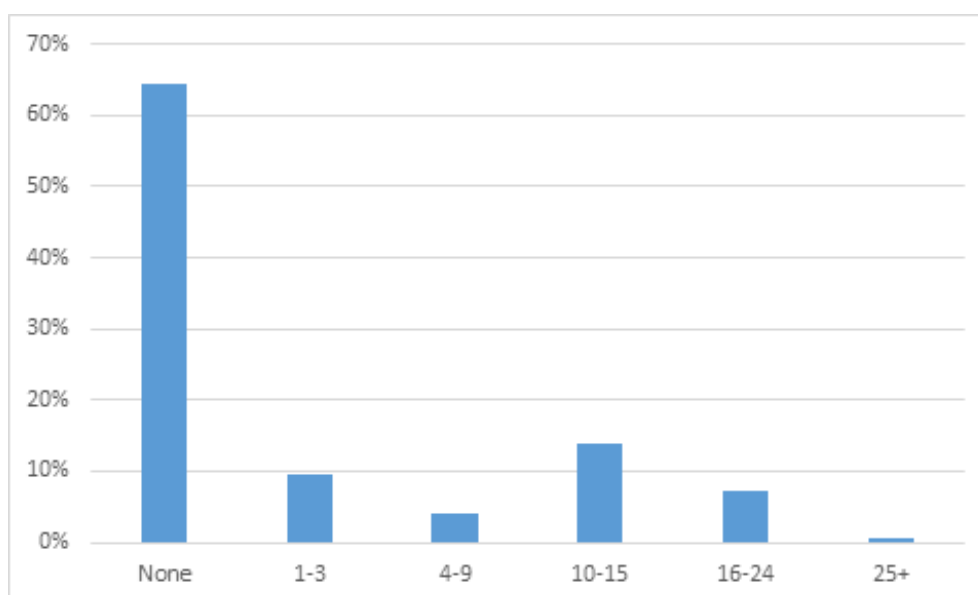


the needs of the carer, allowing HCC to understand the best way to support people to maintain their own health and wellbeing whilst balancing caring with other aspects of their life. Support offered by HCC (but sometimes provided by voluntary sector organisations) may include:

- Short breaks - ranging for a few hours to meet a friend to residential care
- Nursing home placements to allow up to two weeks break
- Direct Payments for a service to support the carer
- Emotional support from other carers or from people who understand such as Carers' Support Workers
- Help with household tasks
- Help with caring tasks
- Financial benefits advice
- Activities for the person who is cared for

Of the people who responded to the survey by saying that they did receive extra support from an informal carer, we went on to ask how many hours per month that person received in 'respite' care to allow them a break. 65% of respondents reported that their informal carer received no respite at all.

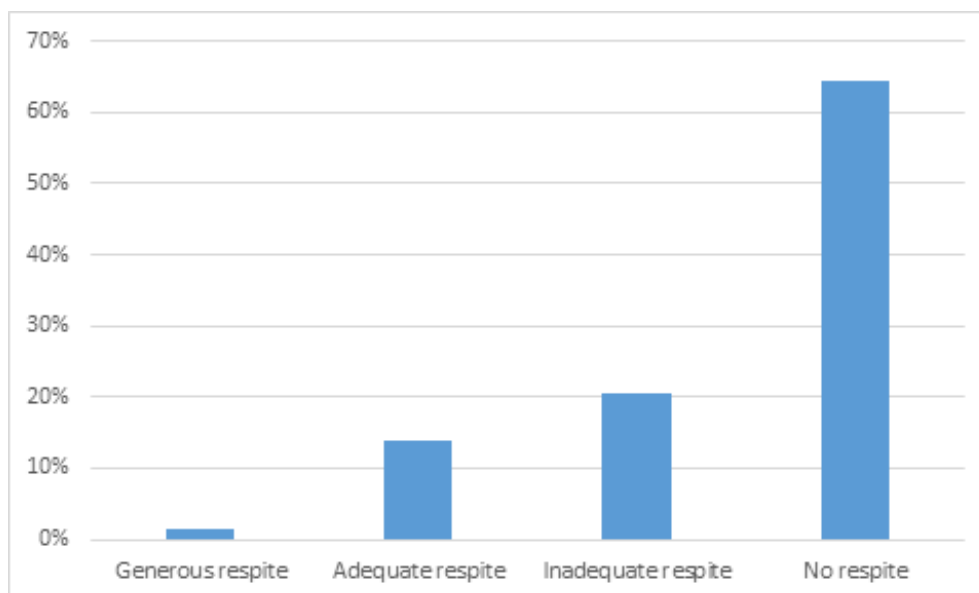
If 'Yes', how much 'respite' do you receive per month (hours) so that your usual informal help can take some time off? 446 responses



Of those that responded to say that their informal carer did receive some respite only 15% said they felt this was 'adequate' or 'generous'.



If you do receive respite funding so that your informal carer can have a break, do you think you get a reasonable amount, in view of the input received from the informal carer? 515 responses



Figures published by Carers UK show that 1 in 8 adults (around 6.5 million people) are carers. By 2037, it's anticipated that the number of carers will increase to 9 million. Every day another 6,000 people take on a caring responsibility - that equals over 2 million people each year. Carers are estimated to save the economy £132 billion per year, an average of £19,336 per carer. People providing high levels of care are twice as likely to be permanently sick or disabled and over 1.3 million people provide over 50 hours of care per week. (Carers UK)

Research suggests that people miss out on vital support because they don't recognise that they have taken on a caring role. For many people, looking after an ill, older or disabled loved one doesn't have a name, it is 'just something you do' If you do not see yourself as a carer, then you are unlikely to consider asking for a carer's assessment, applying for Carer's Allowance, or seeking advice from others who find themselves in similar circumstances.

The results of this survey suggest that many informal carers are not accessing support to which they may be entitled.

"My parents look after all my needs and they need these breaks I don't want to have to argue my point over all time they should be listened to as it is what I want and they know this - This needs to be looked at and not ignored."



“I find this survey hard to answer as I am a full-time carer for my father and am disabled myself. I get 3 hours a week ‘take a break’ hours and am supposed to be able to get Dad into respite care for 2 weeks a year - There is NO respite to be had. . After my recent experience, I would say “what care at home service”? I was 999’s into hospital with a life-threatening illness my father was left alone at home. I had put in place an Emergency care plan with the princess trust for carers. Friends rang them they could do nothing - Social Services rung they manage to get dad 15 minutes a day care to get him a meal.”

If you provide informal care support and would like more information about support available for you please visit:

<https://www.hants.gov.uk/socialcareandhealth/adultsocialcare/supportforcarers>

Recommendations

More widespread advertising of carers assessments to ensure that informal carers get the support they are entitled to including information, advice, emotional health and wellbeing support and respite care.

This report highlights the ongoing need for further support for informal carers. We recommend more widespread advertising of carers assessments, by HCC and throughout the voluntary sector network to ensure that informal carers get the support they are entitled to including information, advice, emotional health and wellbeing support and respite care.



Thanks

This work would not have been possible without the support of numerous people who gave up their time to talk to us about their experiences - thank you to all of the carers who contributed. We would also like to thank all of the professionals that we worked with throughout this project. Special thanks go to the staff of the Princess Royal Trust for Carers in Hampshire for their help and assistance throughout the project.



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